

DataSpeak
Transcript
January 19, 2012

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Good afternoon, everybody, welcome to today's program. Findings from the 2009/2010 National Survey of Children with Special Healthcare Needs. My name is Michael Kogan and I'm the Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation at HRSA. The DataSpeak series is sponsored through the Office of Maternal and Child Health Information Resource Center. We are excited to discuss the purpose, methodology, key findings and ways to access both state and national data of the 2009/2010 National Survey.

First, I'll be giving background information on the history, purpose, content and uses of the survey. Our second speaker, Dr. Stephen Blumberg from the National Center for Health Statistics at the Centers for Disease Control and Prevention will discuss the methodology and design of the survey. Our third speaker, Dr. Bonnie Strickland from the Division of Services for Children with Special Healthcare Needs here at the Maternal and Child Health Bureau will present new data from the survey describing the status of systems of services for children and youth with special healthcare needs in the nation and the progress made toward the six systems quality indicators and national performance measures. Finally, Dr. Christina Bethell from the National Data Resource Center for Child and Adolescent Health at the Oregon Health and Science University will present on accessing and using state and national survey data through the Data Resource Center. Now, before I begin I'd like to introduce Sarah Lifsey the moderator for today's program. Sarah?

Sarah Lifsey

Thank you, Michael. First, I'd like to welcome our presenters and everyone who is in the audience today. Thank you so much for joining us. But before we begin the presentations, I have some brief technical guidance. First, I'd like to call your attention to the DataSpeak website, which we hope you will visit after today's program. There you'll find resources on today's topic including some that our speakers will highlight in their presentations. On the website you will also find archives of all the DataSpeak programs going back to 2000. The slide on your screen shows some of the most recent programs that are available and the address you can use to access them. I'd like to point out that you are able to download today's PowerPoint presentations directly from the screen that you are seeing right now. Click on the presentation that you are interested in to highlight it on the left under downloads, click save to my computer and follow the simple instructions on the screen.

If you would like to make the slides larger simply press the full screen button at the very top of the slide view that you are seeing. Finally, if you are listening on the phone and cannot access the webinar on your computer you can download a copy of the slides from the DataSpeak website, simply go to upcoming events, select this webinar and go to additional resources to find the slides.

Finally, please know that your phone line will be muted during the presentations. At the completion of the program we'll be having a question and answer session and we will provide instructions for asking questions over the telephone at that time. If you'd like to pose the question online you can do so at any time during the program using the questions box on the bottom side of your screen, just type your

question in the box next to the arrow and hit enter. Now I would like to turn it over to our first speaker, Dr. Michael Kogan. Michael?

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Thanks very much Sarah. I am going to begin by talking about the purpose of the National Survey. The primary purpose is to measure and track the prevalence of children with special healthcare needs both nationally and at the state level one of the things that makes this survey unique. We can also describe their characteristics. It also looks at their health and their experiences with the healthcare system. Further, this survey also tries to describe the impact of having special healthcare needs looking at functional limitations, healthcare access, needs and satisfactory care, and the burden and impact on the family. Later, I will talk about the different sections of the questionnaire.

There have been a number of uses for the National Survey data in the past and we continue to use them for these purposes. For the first one, it tracks the core outcomes for systems of care for children with special healthcare needs required by the Title V legislation. Secondly, data from this survey and from previous surveys have been used to measure healthy people 2010 objectives and will be used for healthy people 2020 objectives. They have been used to planning and program development in numerous states, at the state level and this is now the third round of the survey. The first one was in 2001, the second one was in 2005/2006. So now we can look at changes that have occurred since 2001 and we now have the ability to look at trending data over the past decade.

Next, these data have been used to inform numerous organizations that work directly with children with special healthcare needs. And finally, about 250 publications have come from previous surveys both the National Survey of Children's Health and the National Survey of Children with Special Healthcare Needs. We anticipate this productivity to continue with this survey.

In this survey, and all surveys children with special healthcare needs have been defined as those children who have or are at increased risk for chronic physical, developmental, behavior or emotional conditions, and who also require health and related services of a type or amount beyond that required by children generally. This is the definition that has been used by MCHB and was published in pediatrics in 1998.

The way we select children with special healthcare needs is through a children's special healthcare needs screener, which is a five item parent report tool. Parents were asked if their child needs or uses medicine prescribed by a doctor, needs or uses more medical care or mental health, or education services than is usual for most children, is limited or prevented in the ability to do things, needs or gets special therapy, and needs or gets treatment or counseling for an emotional, developmental or behavioral problem. There are then two follow-up questions, if the parent reported yes to any of those previous five questions they were then asked is this due to a medical, behavioral or other health condition and is this a condition that has lasted or is expected to last 12 months or longer?

In 2009/2010 in this national survey we found that the prevalence of children with special healthcare needs was 15.1% and this is significantly higher than it was in 2005/2006 when it was 13.9%. The 15.1% would translate into about 11.2 million children in the country who have special healthcare needs. The prevalence of kids with special healthcare needs ranges from 10.6% to 19.8% across the 50 states and the District of Columbia. Further, more than one in five households with children in the United States have a child with special needs.

When we look at the prevalence by certain demographics, we find that boys are significantly more likely than girls to have a special need, 17.4% to 12.7%. By age you see that school age children are significantly more likely for their parent to report to be screened in as having a special healthcare need, probably because some conditions may be less apparent until a child enters school.

What you see on this slide is that there is a decreasing prevalence, for the most part of special healthcare needs, with increasing income. As I mentioned earlier, there are a number of sections to the questionnaire. In addition to the demographic data there is a wealth of information on their experience with the healthcare system. So, there are questions on health and functional status, questions on chronic conditions and functional difficulties, access to care utilization, unmet need, medical homes, satisfaction with care, both health insurance, presence of health insurance and health insurance adequacy. There are questions on transition to adulthood for older adolescence and questions on impact on the family.

We feel we have made some improvements to this survey in relation to the previous survey. First, we now ask about level of functional difficulties. We asked about 14 different types of functional difficulties and more than 90% of kids with special healthcare needs experienced at least one functional difficulty. We improved the questions on the prevalence and severity of chronic conditions. We asked about 20 specific conditions. We now distinguish between whether the child currently has a condition or whether they were ever told they had that condition in the past. Again, we asked about severity, whether it's mild, moderate or severe and specifically for autism spectrum disorders we asked the age which the child was diagnosed.

In terms of the impact on the family, we now ask the question on whether parents avoided changing jobs because of concerns about maintaining health insurance for their child. We have added some completely new questions in this survey. We now ask about the impact of emotional behavioral developmental conditions on daily life, early intervention services, complementary and alternative medicine, finding about 1 out of 10 children with special healthcare needs use complementary and/or alternative medicine, developmental screening, and then for children who are reported to have Attention Deficit Disorder or ADHD we now ask about medication and treatment.

Dr. Strickland is going to talk more about the core outcomes for the Maternal and Child Health Bureau and there have been some changes in the measurement. For medical home the only change we had here is that all interpreter questions were deleted in the 2009/2010 survey, but we believe they are comparable and because the rest of the content is comparable between the two surveys. For outcome number four, which is early and continuous screening, we changed the question slightly so that now we ask about number of well-child and preventive dental visits, they must have both now in the questions. We changed that to match the National Survey of Children's Health. So, it may not be appropriate to compare the 2005/2006 surveys with the most recent survey.

There were two outcomes that were changed completely. One is shared decision making and we completely revised that content, it is not comparable to the earlier survey. We now ask questions on how often did the healthcare providers discuss a range of healthcare options, encourage you to raise concerns or ask questions, make it easy to ask questions or raise concerns, and respect the health and treatment options that you thought would be best.

The second outcome that was changed completely between the last survey and this one was ease of using services. In the past survey we asked one question how easy was it to use services and so rather

than do that again we tried to ferret out the information much more, so we asked questions about the difficulties or delays in getting services for your child and we asked about the reasons, such as he or she was not eligible for services or the services were not available in the area. We asked about waiting lists or trouble getting the information needed and then we asked about any other reasons.

So, I would like to acknowledge the contributions to this presentation of Dr. Christie Bethell and Jessica Jones. And this is my contact information. Thank you very much.

Sarah Lifsey

Great. Thank you so much, Michael. As a reminder to all of the people watching and listening, if you have a question for any of our speakers you can submit it on-line at any time using the Q&A form on the bottom of your screen. If you are listening in on the phone and unable to log in on-line we will have phone questions at the end of the program. Also, you can go to the DataSpeak website and download the slides for today under upcoming events if you are unable to get on-line to view them. Next, I would like to turn to our next speaker, Dr. Stephen Blumberg.

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

Thanks, Sarah. My role here today is to talk about the methodology and design of the survey, to get a little bit technical. But, for those of you who are already familiar with the National Survey of Children with Special Healthcare Needs, much of this is going to sound the same, because a lot of it is the same in terms of the design since 2001 and 2005/2006. So, the National Survey of Children with Special Healthcare Needs is a random digit-dial telephone survey, which means that we randomly generate telephone numbers in all 50 states and the District of Columbia and then we make a lot of telephone calls to try to identify households and to learn whether the households we do identify have children. Once we find a household with children we screen all of the children in the household for special healthcare needs.

Now in 2001 and 2005/2006 we limited ourselves to landline telephone numbers. However, we know that today more than 36% of children are living in wireless only households and therefore it was important in 2009/2010 for us to supplement the sample of landline numbers with an independent random digit-dial sample of cell phone numbers. When we contacted parents, on a cell phone, we asked them if they had a landline telephone and if they did whether they were likely to answer that phone when it rang. A parent was only eligible to continue to the CSHCN screening and later the interview if their household did not have a landline telephone or if that parent told us that they were unlikely to be reached through the landline if they had one.

When a household includes a child with special healthcare needs that household was eligible for the detailed questions about the health and healthcare of the child. If the household included more than one child with special healthcare needs one was randomly selected to be the target of the detailed interview. Our goal was to complete detailed interviews for 750 children with special healthcare needs in every state and we continued calling in screening households until we met that target. The process took nearly two years with interviewing beginning in July of 2009 and ending in March of 2011.

The respondent was a parent or guardian who was knowledgeable about the health of the child, this is usually the mother. The interview lasted on average about 33 minutes and was conducted in English, Spanish and four Asian languages. About 50,000 households that completed the CSHCN screener got a small monetary incentive for completing it, about 10-15 dollars. So, overall we talked to nearly 200,000

households with children and screened more than 370,000 children in those households for special healthcare needs. We completed more than 40,000 detailed interviews for CSHCN nationally and of those, nearly 3000 were completed by cell phone.

Let's turn now to the various outcome rates for the survey starting with the landline sample. You can see that all of our outcome rates are reasonable. So, for example once we identified a household with CSHCN 83.6% of them, more than 4 out of 5, completed the interview. However, about 1 out of 5 telephone numbers rang without an answer or were picked up and hung up without anyone saying anything and this is shown in the resolution rate of 81.2%. Outcome rates for the cell phone sample were smaller across the board most notably when we look at that resolution rate. Cell phone numbers simply are more likely than landlines to ring without an answer, to be picked up and hung up without anyone saying anything or to go to a generic voicemail from which no one ever returns the call. This might suggest to some that the potential for nonresponse bias is greater for the cell phone sample than for the landline sample, but we don't think this is the case.

A realization rate is a measure of a survey's ability to identify and interview the target population and when we compare the realization rates between the landline and cell phone samples we find that both samples have nearly identical rates. The National Survey data collection was conducted by the SLAITS mechanism at the National Center for Health Statistics. SLAITS stands for the State and Local Area Integrated Telephone Survey and it is a mechanism for conducting high quality telephone surveys in a cost effective way. It is a mechanism that has been used not only for the National Survey of Children with Special Healthcare Needs but also for the National Survey of Children's Health, the National Survey of Adoptive Parents and several others.

And when people talk about the SLAITS survey it is not always clear which survey they are talking about and that is why we tend to prefer to use the actual survey name. However, it is important to remember that the National Surveys are conducted using the SLAITS mechanism because when you go looking for the data files or the questionnaire on-line you need to go to the SLAITS page on the CDC website. The link to that page is actually the link specifically to the National Survey of CSHCN homepage is given here on this slide. There you will find data files, questionnaires, codebooks, sample SAS programs, instructions for formatting the SAS data files and most importantly you will find a document of frequently asked questions. And those frequently asked questions is a short methodology report about the survey. We do not yet have the complete design and operations report available for distribution, but most of the information that you would need in order to analyze the data is in this frequently asked questions document. Most importantly, I want you to pay attention to information about sampling weights, about estimating variance and about using the cell phone sample, because the addition of the cell phone sample has changed the procedures that people need to do when they are trying to calculate confidence intervals, standard errors or get appropriate odds ratios.

Now coming soon, I mentioned the design and operations report, we are working on that and we hope to have that out soon. But, before that you should be able to find some new data files that we are anticipating coming out within the next few weeks. These data files are imputed data from variables for which we had elevated item nonresponse. Item nonresponse was elevated for household income, that has been true every year, but this year it was also elevated for race, ethnicity, primary household language, parental education and receipt of TANF cash assistance or welfare. We will be releasing multiply imputed data for all of those variables and I would caution that CSHCN prevalence estimates should not be estimated for these subgroups without using the imputed data.

Coming soon also will be data from a follow-up survey to the National Survey of Children with Special Healthcare Needs. This is the survey of pathways to diagnosis and services. The National Institute of Mental Health using Recovery Act Funds funded a follow-up to this National Survey of CSHCN in order to obtain more information about school age children who have been identified as having ever been diagnosed with autism, intellectual disability or developmental delay. The respondent is the same person, parent or guardian who responded to the National Survey and that parent was asked a series of questions about the original diagnosis, who provided it, what was the presenting concern, have other doctors or healthcare providers given similar diagnoses to the child? Have you received second opinions that indicated that your child may have a different diagnosis? We asked about a history of clinical service use looking at about 15 or 16 different services for children with these developmental conditions.

We asked about current educational service use, parent's perceptions of the disorder, their perceptions of how effective various services have been and we also sent a mailed questionnaire home to these parents so that we could get some details about current symptomatology and impairment levels. About 70% of the parents we contacted completed the telephone interview, so ultimately we have this detailed information for more than 4000 children with a history of having a developmental condition. There is my contact information and I look forward to answering questions at the end. Thanks.

Sarah Lifsey

Great. Thank you so much, Stephen. As a reminder, if you have a question for our speakers and you are logged into the web conference interface you can submit it any time using the form on the bottom of your screen and if you are just on the telephone and unable to get into the web conference we will have time for telephone Q&A at the end and you can also download a copy of the slides so you can follow along from the DataSpeak website. Now, I would like to turn to our next speaker, Dr. Bonnie Strickland.

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

Well, thank you Sarah and hello everyone. I would like to take a few minutes to provide an overview of where we stand on the six system's quality indicator for children with special healthcare needs. These indicators are also the national performance measures for children with special healthcare needs. Many of you may remember that the Omnibus Budget Reconciliation Act in 1989 established the requirement to facilitate a system of services for children with special healthcare needs. This was a new vision for children with special healthcare needs because it went beyond treatment to really looking at the entire system. However, that vision did not include a definition of children with special healthcare needs nor did it define that system of services that the legislation required. And so we spent approximately the next decade defining children with special healthcare needs and defining what we meant by a system of services for children with special healthcare needs.

Then in 2001 the National Survey of Children with Special Healthcare Needs provided the opportunity to, not only establish prevalence for that definition of children with special healthcare needs that Michael was talking about, but also to monitor progress toward what then were newly defined indicators of that system of services. Here is the definition that Michael referred to earlier, you can see that it goes far beyond the long-ago definition of crippled children and only children who were eligible for supplemental security income.

Here you see the six quality indicators, also national performance measures for children with special healthcare needs, the partnerships with families and youth, access to care through the medical home,

adequate financing, early and continuous screening, organization of services for easy use, and transition to adult healthcare. We are going to come back to these in just a minute.

But, first I would like to say a few words about the attributes of the monitoring system, as well as the way we measured each one of those quality indicators. The system that we used to monitor our progress, The National Survey of Children with Special Healthcare Needs, works well for us in many ways. First it is multi-level. As Michael said it gives us both national and state level measurement. It provides multiple time points to measure our progress from baseline in 2001 to the intermediate measurement in 2005 and 2006 and for an end point, right now, of the 2009/2010 data and hopefully there will be many more points in the future.

It is also sensitive to detecting bottlenecks for a couple of reasons. One, each of the indicators are broken into components and subcomponents. So, for example with a medical home we can see whether the bottleneck is in usual source of care or if it has more to do with the qualitative aspects of medical homes such as care coordination or family centered care.

Secondly, the surveys provide us information about populations responding to the survey, so we can also tell which populations of children are fairing better or worse in relationship to each of the indicators. And finally, the measurement approach is cost effective to implement for all of the reasons that Stephen just said. We already have an existing infrastructure with the National Immunization Survey and the SLAITS mechanism.

So, how do we construct a measurement approach for each of these indicators? First, each one of the indicators is disaggregated into components and subcomponents. For each of the components criteria were established that can be measured using the national survey and successful attainment of an indicator is based on a sample child meeting the criteria for all of the component items and then the results are summed across the entire sample to produce national level estimates of how well we are doing and then the same approach is used at the state level.

So, let's go back then to the indicators themselves and see how we are doing. Quality indicator number one, families of children with special healthcare needs are partners in decision-making. You can see the subcomponents here, doctors discuss the range of treatment options and encourage questions, and make it easy to ask questions, and consider and respect family choices. You can see here that in 2009/2010 about 70% of families could answer usually or always to each of these and thus achieve the component.

Quality indicator two, children with special healthcare needs receive coordinated care within a medical home. Again, you can see the components here, usual source of care and preventive care, sick care, and personal doctor or nurse, and no problems obtaining needed referrals, and needed care coordination, and care provided that is family centered, and also meets each of these subcomponents. You can see here that in 2009/2010 43% of children received care in a medical home, that is they met all of those indicators, subcomponents and components. However, if you look at 2005/2006 and remember this indicator is comparable to 2005/2006 we had 47% in the previous survey. So, we have had a significant decline in the proportion of children who have access to a medical home in the recent survey.

The third indicator are children who have an adequate public or private insurance to pay for the services they need. Here you see the components, they have insurance at the time of the interview and they have had no gaps in coverage and the insurance meets the child's needs, the root costs not covered by

insurance are reasonable, and the insurance permits the child to see the providers he or she needs. Again, this indicator was comparable to the 2005/2006 survey, but like with the medical home we had a significant decline from 62% to just over 60% of children who met this indicator.

Indicator four is children are screened early and continuously for special healthcare needs. This means that the child had a routine preventive visit in the past year and had a routine dental visit in the past year. This indicator was not comparable, but you can see that over 78% of children met this indicator.

Indicator number five is community based services for children with special healthcare needs are organized so families can use them easily. And here you see the components and subcomponents of this indicator. No difficulties or delays getting services and again, as Michael showed you can see the subcomponents here, and the second component was there was no frustration when trying to get services for the child. This indicator was not comparable, in fact it was completely changed from the previous survey, but you can see that 65.1% of children met this indicator.

And finally, youth with special healthcare needs will receive services necessary to support the transition to adulthood. Here are the components and the subcomponents. The child receives anticipatory guidance in transition to adulthood, that means the doctor discusses the shift to adult providers, discusses the future healthcare needs of the youth and talks about future insurance needs, and the youth has been encouraged to take responsibility for his or her healthcare. This measure was comparable to the 2005/2006 survey and although the decline is not significant, you can see that we drop from 41.2% to 40% in the most recent survey.

So, how many children, what proportion of children meet the requirements of all of these indicators and thus are receiving care in a well functioning system of services? Well, only a small percentage of children in youth actually receive services in a system that meets the criteria for a well functioning system, that is they meet all of the requirements, 20.2% of children with special healthcare needs birth through 11 met all five indicators, only the first five applied to them and only 13.6% of children in youth ages 12 through 17 met all six indicators.

So, where do we stand? Although a strong national foundation exists for the indicators, overall progress from the 2005/2006 survey, on medical home insurance and transition just has not occurred and the other indicators are not comparable. We also continue to find that children with significant special healthcare needs continue to fair less well than those with less significant needs. As with other surveys and previous survey's the disparities continue to exist based on poverty, race and ethnicity and as a parent that we need to identify and focus on changing influential components of each of the indicators, especially those qualitative aspects of the indicators to increase our success rates.

And finally, the indicators set a very high benchmark for attainment. It is obvious that raising rates of attainment is going to require reforming the healthcare system and this is a daunting but important task. Thank you very much. Here is my contact information.

Sarah Lifsey

Great. Thank you so much for that. As a reminder to everybody on-line and on the phone, if you have a question for our speakers you can submit it on-line anytime using the Q&A form on the bottom of your screen and at the end of the program we will have time for phone questions and answers as well, and I would like to turn to our last speaker, Dr. Christina Bethell.

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

Thank you, Sarah. I am so pleased to be here with all the people on the phone and have an opportunity to join you today. You have heard from Michael, Stephen and Bonnie about where the survey came from, its purpose, its methods, and some key findings, and my goal is to wrap it up by sharing more about how to access and use the data.

So, why we need data? We have been talking about it all day, but Michael pointed out that this survey combined with the other survey, National Survey of Children with Special Healthcare Needs, actually provide data on 75% of the core needs and priority topics that have been identified by Title V Programs across the country in their Block Grants and needs assessment. So, these are very important data sources. Clearly data is essential to building partnerships and being able to have a conversation about what it is, how we are doing, where we want to go, and whether we have improved, and also to educate ourselves and get on the same page and these datasets are especially powerful for that because they are standardized and you can actually have a conversation across states or areas and across subgroups and populations, which is a very powerful feature that allows us to speak coherently and address questions that matter. And of course grant writing and research are obvious.

So, my goal today is to share with you about the data resource center for child and adolescent health which is one of the national centers supported by the Maternal and Child Health Bureau and I am going to focus on the website component of the data resource center and share a little bit more about what resources are available in addition to the website. This is the website and what it looks like and the available datasets are both the National Survey of Children with Special Healthcare Needs, the three that have been done on this, as well as the National Survey of Children's Health, which does provide data on children with special healthcare needs as well for a variety of additional indicators.

So, what features are available on the data resource center website? First of all, learning about the surveys. Stephen talked about the methods, manuals and a lot of details and what we do is we work collaboratively with Stephen and his team as well as MCHB to try to translate those manuals into more user friendly documents that you could potentially pass out to key partners and those that you would like to engage in using this data and so that is available, search and compare at both the item level as well as the measure level, the measures Bonnie mentioned, at the state, national and regional units of analysis as well as by many subpopulations.

So, there are over 100 indicators across the two surveys and they cover topics for Title V we have been discussing as well as many healthy people 2020 goals and many of the measures have actually been endorsed by the National Quality Forum for use for those of you who are engaged in the national focus on quality measurements and improvement for children.

So, let me just give you a little bit of a visual tour and for those of you who are in a place where it is safe for you to do so you are welcome to log onto the website as well at childhealthdata.org and you can follow along. So, this is just showing that we have FAST FACTS and also it is just a little flash of what that looks like summarizing a lot of what Stephen mentioned is in the manual and also a visual of the sampling frame. In addition, we take the caddie, which is quite a long document and complex to figure out what denominators are and skip patterns are and actually translate it into a short quick guide and what you can do is take the quick guide on-line click on an area and it will actually pop up the exact

question that was used. And then we have pop up boxes that can give you more information about the item and how it is used in measurement.

So, what data can you get on the website for querying? First of all, interactive data snapshots, which bring together a number of indicators into one profile at the state level and you can compare it to other states, the nation and so on. There is interactive state ranking tables where you can actually look at all states at the same time for any one indicator by a subgroup and then get maps as well to look at indicators across the nation more visually and whether they are distinctly different. And then there is the interactive query where you can just go one by one by one every single item or indicator searching by area population subgroups and comparing across areas and so on.

So, I am going to give you what we call our 360, it is not quite 360, but almost, it is probably like 280 degree tour, but it is the quickest way to get oriented and so here on this slide you are seeing I have a circle of the US map. So you just basically click on browse data snapshots and it takes you to a map and you click on your state, and then you get a choice of a number of state profiles that you could look at. I am picking the comparison between the two years of the 2009 and CSHCN overview that is available at this time. And what you can do there is, they are interactive in the sense that you can go to an indicator and click on it and it will then take you into the more detailed query where you can start looking at your state by subgroups back and forth, and so that is a way to look at the global view and then get right into the in depth data query and you have both tabular and graphical displays that can be copied and pasted into documents. We do provide confidence intervals and raw and weighted population estimates.

And this is just a view of subgroups. I am looking at type of insurance by a medical home for example and then you can see that it shows you that. And at this point it is a three-way cross tab, so you have to pick this outcome that you want whether it was successfully achieved or not successfully achieved. This is comparing across types of insurance and you can see that is the table there.

Okay, so subgroup comparison options are varied and they are not always the same for every single indicator for methods reason, but these are an example of all 50 states, age, sex, race, ethnicity, primary household language. We will have household income imputed, those files are almost ready, and those will be there. We create a couple of different versions of income to also match with CHIP eligibility, family structure, special healthcare needs status, and a number of different subgroups of special healthcare needs, types of special needs, and so on. So, if there are subgroups that start to look really prominent and important we will add them. So, we welcome your suggestions for that.

So, from the query at any point you can actually pick all states as the geographic unit of analysis that you are interested in. I am just showing a visual there and then you can just rank all the states by any of the indicator outcomes that you are interested in. You can also then click on the state that is the state of interest. And I am circling California here and that will actually get you back into the query as well where you can start going back and forth and then you can go back to looking at all states and so on.

Okay, so now I am just going to take a couple of more minutes to tell you a few other things that are available. There is trending now across years, so here you can see for a measure or indicator, or survey items that can be trended you have an option to compare this measure across yours just by clicking on that feature on that page and it will show up proactively so you will know. There is also the map, which I mentioned before, and if you click on your state it will pop up a table that gives you the detail of how your state compares to the nation.

An then other features are topically focused data snapshots, getting expert help, you can e-mail us or call and we work with a lot of people on their data use needs and confirming their understanding of the data and also getting other resources on how others are using the data. Here are a few examples of some profiles, these are on each of the core outcomes, which are available now, as well as we have a summary of the whole system how Bonnie mentioned looking at all children across all the core outcomes and we have a summary of that too. Who are children with special healthcare needs, condition specific profiles and so on?

For technical assistance just go to ask a question, there is a range of options for what we can assist you with including getting access to datasets and interpreting your results, conceptualizing research sometimes if there are questions about how the variables, what they really are and are not, and that is actually really important. We do as much as we can to educate about what they are, but there are subtleties that cannot be communicated completely.

So, finally is a feature around downloading, cleaned and labeled datasets, so there are three datasets that go with the National Survey of Children with Special Healthcare Needs. We actually merged them together and create a interview file data set that has all the variables coded and we have code books as well and SAS and SPSS and we will be including the imputed income variables and other variables as well and the reason the datasets are not available today or soon is because we are waiting for that, but I encourage you to use them they can fast track your use of the data, especially if you do not have a lot of time or interest in being able to download them in a more raw form. But it is also nice to do both and compare if you would like, it can be a good training exercise.

So, I want to end with just saying that there is a lot more to share about the data in terms of the exciting information, which is variation that is impaled in the data there. So, I really encourage you to go and start looking as well as let us know what your interests are, because we would like to really tailor and partner with data users to put together either new snapshots or variables that are of key interest to the populations. So, have a good time and I encourage you to use the data also to tell a story to partners, for example, Michael mentioned 11.2 million children with special healthcare needs, which actually is equivalent to about 204,000 school buses filled with children with special healthcare needs, which actually spans almost the entire Atlantic Coast. So, there are some interesting ways that we can share with you about how to report the data as a salient to the policy and program leader users that are really important to have an out, and family advocates, and others who we really need to reach out to with this information. So, thank you very much.

Sarah Lifsey

Great. Thank you so much and thanks again to everybody who has presented today. It has been a great program and we already have quite a lot of questions going in and just a note for everybody who is logged in, because of the volume of questions we have we are actually going to roll a little bit past 3:30, maybe 10 minutes or so past 3:30, so if you would like to stay on the line with us we are going to try to answer a lot of the questions that we have received. As I mentioned at the beginning, we are able to take questions both on-line and on the telephone. To post a question on-line just enter your question in the field at the bottom of your screen and hit enter. And to ask a question on the phone just press *1 to indicate that you have a question; the operator will let us know that there is a question and will indicate to you when to go ahead and ask your question. And so while folks on the phone are joining the queue I am going to start with a few of the on-line questions that have come in.

The first question I have is really for all of our speakers. It is from Taletha and the question is what are your thoughts on the drivers of the increase in prevalence of children with special healthcare needs from 2005/2006 to the current data set?

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

Do you want to name somebody to answer that?

Sarah Lifsey

You can go ahead and answer it.

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

Okay, well first of all my first answer is that is an observation and that requires more in depth analysis to be able to answer that coherently at this moment. So, that is a process that is underway to examine that. There were some small method changes in the survey that need to be looked at first and then we do have information from other ways of identifying children with chronic conditions and special needs that indeed it does look like there are some increases in certain areas from the most recent NSCH we saw autism spectrum disorder and in particular some mental, behavioral, emotional issues that also seem to be increasing and so there is a variety of publications that taken together could really account for the increases that we are seeing, but that is actually a very specific analysis that you can count on many people to be looking at in the future.

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

I have nothing to add to that.

Sarah Lifsey

All right. Great. The next question I have I think is probably for Michael and we got it from a few people. The question is why were the interpreter questions deleted? And what were the interpreter questions? Can you speak to that a little bit?

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Yes. The interpreter questions were, there was a question of did you need an interpreter to communicate with a physician and we had very, very low response for it, very, very few people answered yes to that. So, it really would not have changed the overall composition of medical home.

Sarah Lifsey

Okay. Great. The next question I have is from on-line, it is from Frank. The question is, how did you decide to choose 750 children per state? Where did that number come from?

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

I can jump in there. That number has been consistent since 2001 and in the work that we did prior

to 2001, prior to the first National Survey of Children with Special Healthcare Needs 750 per state was found to be about right in terms of what was necessary for sufficiently precise estimates about the characteristics of CSHCN in a given state.

Sarah Lifsey

Okay. Great. Thank you. I believe that we have a question on the phone?

Operator

This is a question from Margarita Gay. Please go ahead.

Margarita Gay

Can there be future plans to have Guam participate now in the survey?

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

This is Michael, I will take that. Unfortunately at this time, there are no plans to expand it beyond the 50 states and DC because it gets into issues of the phone coverage in certain areas or the percentage of households that are covered by telephone and also cost issues as well of course.

Margarita Gay

Okay. Thank you.

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Sure.

Sarah Lifsey

Great. My next question that I have from on-line from a few folks including Linda, is whether the survey reports smaller geographic units than state, for example zip code or county level information?

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

Well, we do collect information about zip code and you can translate zip code then to county level data or county level identifiers. So, that information is available internally here at the National Center for Health Statistics, however, we do not release those data publicly for confidentiality reasons. We need to protect the confidentiality of the participants in the survey. We also do not weight at the county levels. So, you could not simply take the subpopulation of children who we may have found in a particular county and assume that they are representative of the county population without doing some additional work on the weights. However, those individuals who are interested in doing research where they want to match up say some county information with data from the National Survey of Children with Special Healthcare Needs to do some sort of contextual analysis can get access to those county level identifiers through the NCHS research data center.

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

And this is Christie. I am just going to add that there is an opportunity to construct synthetic estimates using county characteristics and stratifying by those characteristics and we have actually a little

document at the data resource center to guide people on how to do that and obviously there is a lot of data used in the United States for policy and program planning that is based on synthetic estimation approaches and so it is a consideration you have to consider but that is something that is possible and if you would like some examples for how to do that we can support you in that.

Sarah Lifsey

Great. Thank you. The next question I have is another one from on-line from Heather and it is, given the growing body of research on the connection between exposure to violence and chronic medical and behavioral issues are there any questions or are there any plans to include any questions that can be used to collect more data to further support the research on that theory?

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

I can take that. At this point there are no plans to add questions about exposure to violence to the survey. Every time that we are planning a new survey we certainly put out a call for questions of interest and vet them with a technical expert panel. One problem however of asking questions about exposure to violence for children when talking to the child's parent is that in some cases the parent may not know about that exposure or may be the vector through which the child is exposed to violence and therefore it is unlikely that we would get accurate information.

Sarah Lifsey

Okay. The next question I have is from Catherine and it is in the context of children's special healthcare needs how would you define complementary or alternative healthcare?

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

This is Christie and we worked on that with the bureau and with only the option to include one item and so in cognitive testing we focused on asking it so that it got out information of whether they had seen providers. So, it does not include the wide range of products and practices that might also be considered complementary and alternative medicine. However, we have compared the data to a more comprehensive national health survey supplement on looking at CAM use and there is a lot of consistency for children with ongoing health issues who have an above routine with the services. So, for those of you who are interested in that we will have a summary on that and are working on it, because it is a new measure and so there will be special attention given to its validity, properties and findings. And there is an item, if you go on the website you can actually pull up the exact item using that guide to topics and questions asked that I mentioned to you earlier.

Sarah Lifsey

Great. Thank you. I have another question, I think probably appropriate for Christie from Jennifer. For the trending, are trends analyzed for statistical significance and can you compare trends between groups?

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

Well this is something we are spending a lot of time on at the data research center and I also know that is true for various researchers at the bureau and many of you will be interested in that, so I do not want

to claim any perfect answers to this, but I will tell you that there are limits in which items and which measures can be trended and that is made clear on the data resource center website. It will also be made clear in the code books and issues that will be noted about trending, because people will have different opinions about whether items can or cannot be trended. So, that will be available and we have already got on the website those that we will be adding additional that can be trended. In terms of statistical testing you are provided, at least on the DRC, the raw end and the confidence intervals and you can get some information there but you really need the standard errors and an adjustment process to do that properly and you would need the data set for that. If it is a simple run we can often support that here at the data resource center. But that is going to, again, be a topic of great interest to many of you as well as the Maternal Child Health Bureau and all of us here. There will be a special button on the data resource center where you can actually view all of the items and indicators that are considered to be trendable either across two or three years and right now though you can go into the query and if compare this across here shows up that is already an indicator item that the technical team has agreed can be trended.

Sarah Lifsey

Okay. Great. The next question I have also from the on-line entries is from Janet and I think probably intended for Bonnie. Can you speak to the changes at the state level in meeting outcome number six for transition, even though the difference is not significant at the national level it appears there are changes from 2005/2006 to 2009/2010 for many states. Are there any thoughts about why the rates dropped for so many states?

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

I have not really looked at the state level data at this point. I have looked only at the national data. So, I really could not respond to it. Christie, I don't know if you have looked at the state changes on number six or not?

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

Yeah, I know there are several areas that appear to have changed and obviously there is some validity analysis you just want to examine just to be really careful, because there are subtle changes from year to year in some of the methods and Stephen would really need to consult with us and the others on that, but in terms of variations that is one where there does look to be, and I do not know if there was an increase in discussing health insurance because of the health reform bill, but that actually looks like it increased and others shifted in different ways. So, I think that it is really important to look at program and policy shifts across states and that is one of the opportunities that we have here with this data is to analyze that. Now the issue is giving policy variables that can be compares across states, but I encourage anyone to do so with that one in particular, because that looks very interesting and promising, because maybe we can actually move the bar.

Sarah Lifsey

Great. I do not think we have any questions on the phone right yet so I am going to continue with the on-line questions and I think this next question could really be answered by anybody. It is from Suzanne and it is, do we know anything about international prevalence?

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

I can answer that. This is Christie. Many other countries have used the same screening methodology in their national surveys. Of course, the sampling and the methodology for how they collect the data is different, which does impact the findings. But we do have information on its use in various countries including Germany and others. So, whoever is interested in that if you send in a technical question to the data resource center we can provide you with more information. There are obviously cultural issues and translation issues and methods issues, but so far it is an interesting consistency once children are identified it looks like they have a lot of similarities even if the actual point estimate varies.

Sarah Lifsey

Okay. The next question I have I think is probably for Michael or for Stephen. It is from Anna and it is, do we know if the income status is income before or income after the onset of the special health needs? In other words are children in families with lower incomes more likely to have special healthcare needs or are families with children with special healthcare needs more likely to have a lower income?

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

This is Michael. That is an interesting question. We do not know, this is a cross sectional survey so one of the limitations of a cross sectional survey is you really cannot define the directionality of an association in most cases. In this survey we ask about recent household income. So another way to get at the question would be to look at the very measures of impacts on the family.

Sarah Lifsey

Okay.

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

This is Christie. I just want to say one thing about that often comes up because people miss this sometimes, that while there are the variations that the person asking the question noted, at the household level the prevalence of having at least one child with a special healthcare need is very similar across the different income groups and that strikes me as important potentially because it really is not weighted in terms of the household level, although there are more children for lower income at a household level, more higher income households are potentially just as likely to have at least one child with special healthcare needs. So, there is something about this that might be interesting to note.

Sarah Lifsey

Okay. Great. I think that we have time for a couple of more questions. The next question I have is from Ethan and I think it could go for anybody. I have used the National Survey of Child Health looking at access to healthcare for immigrant children and children of immigrants. Are respondents asked about place of birth or child or parent in this survey?

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

This is Stephen. I honestly do not remember. Sometimes I get the surveys confused and I do not remember if we asked that this year.

Sarah Lifsey

Okay.

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

I do not think we did.

Sarah Lifsey

I assume that they would be able to look on the survey site and probably see the questions?

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

Yes, the full questionnaire is out on the SLAITS website. You can also gain access to the individual questions and full details about them through Christie's website.

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Yes, mostly we ask about language use in the home.

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

Right.

Sarah Lifsey

Okay. The next question I have is from Trish, it is are there any plans to work with the Indian Health Service on doing a similar survey for tribal nations?

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

At this time there is not, but if the Indian Health Service were interested in doing such a survey, we would be more than happy to meet with them to provide assistance and consultation.

Sarah Lifsey

Okay.

Christina Bethell, PhD, MPH, MBA - Associate Professor and Director, The Child and Adolescent Health Measurement Initiative, Department of Pediatrics, School of Medicine Oregon Health and Science University

This is Christie. I can say that in the past this issue has come up and we have done some in-depth work with some folks in Arizona around this topic. So, we could potentially dig that up and share again some of the key issues that arise when considering doing that and there were substantial enough issues that this did not go forward as originally planned, but there certainly are some lessons that maybe somebody could learn if they are considering that that we could fast track them with.

Sarah Lifsey

Great. The next question I have is for Michael. Are there any questions in either the National Survey of Children's Health or this survey of children with special healthcare needs related to substance abuse?

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

The answer would be no.

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

Not in this survey.

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Not in this survey, no.

Sarah Lifsey

Okay.

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

Well, we do ask about need for substance abuse treatment, whether they received substance abuse treatment.

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Yes.

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

Right, under the services section.

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

Right, but not about whether the child was engaged in substance abuse directly, no.

Sarah Lifsey

Okay. Well, I think that we have time for one last question and this question is from Cynthia. To what extent do you think the results from the 2009/2010 survey are due to the economic situation and the current recession especially with regards to access and health insurance coverage?

Bonnie Strickland, PhD - Director, Division of Services for Children with Special Health Care Needs, Health Resources and Services Administration, Maternal and Child Health Bureau

That is a good question.

Michael Kogan, PhD - Director of the Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation

That is a very interesting question and I think we would be foolish not to think that there has been some effect of the recession going on since 2008 and we have researchers here at the Maternal Child Health Bureau who are looking at that question.

Sarah Lifsey

Okay.

Stephen Blumberg, PhD – Senior Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

Sarah let me interrupt for just a moment to respond to the previous question about immigration status. I looked back and we do have questions in the survey about whether the child was born outside the United States or whether the parents were born outside of the United States, but those questions were on the survey this year only for children who lived in California. They were funded by the Lucille Packard Foundation for Children's Health; their focus was on children in California.

Sarah Lifsey

Okay. Great. Well, I think that is all of the time that we have for discussion today. I would like to let you know that answers to the questions that we were not able to address during the Q&A period today are going to be posted in writing with the program archive when it is uploaded in a couple of weeks, that archive will be available on the DataSpeak website and you can access it at your convenience. If you think of more questions you can submit those to us via e-mail through the end of the week using the e-mail address you see on the screen, mchirc@altarum.org, before you go we would like you to know that we will be broadcasting more DataSpeak programs in the coming months, announcements about these future DataSpeak programs will be sent out via e-mail to everyone who registered for today's program and announcements will also be posted on the DataSpeak website.

Finally, before you log out we would really appreciate you taking a moment to provide us with feedback on today's program. It is really important to us that we have your input on this session as well as your recommendations for future programs and future topics. To fill out this very short survey just click on the evaluation link on the screen right now and a survey will open up in a new window. I want to thank all of our speakers today for presenting on this great topic and I want to thank everybody who logged in to listen. Today's program is now complete. Thank you for joining us and have a great afternoon.