DataSpeak: Progress on the Redesign of the NSCH and the Data Resource Center
September 10, 2015, 2:30pm to 3:30pm Eastern

Program Transcript

[Download a PDF of the slide presentation from the [DataSpeak archive](#).
Slide numbers from that file correspond to those noted in this document.]

Introduction

Michael Kogan, PhD
Director, Office of Epidemiology and Research
Maternal and Child Health Bureau

[slide 1] Good afternoon and welcome to today's DataSpeak web conference on the Redesign of the National Survey of Children's Health and the Data Resource Center. I'm Michael Kogan, and I'm the Director of the Office of Epidemiology and Research at the Maternal and Child Health Bureau, which is the sponsor of the DataSpeak series. We have some exciting times around the National Survey of Children's Health. As you know, it's a nationwide survey that exams the physical and emotional health of children from birth through 17 years of age. The survey has been redesigned to include new and revised content, and today's presentations will give you an overview of the redesign and what you can expect from the new survey. The Data Resource Center is a resource that can help optimize the use of this survey as well as other data on child and family health.

[slide 2] We're excited to have with us today two distinguished speakers who perhaps need no introduction, but I'm going to do it anyway. They're going to discuss the purpose of the redesign and ways to use child and family health data. Our first presenter today will be **Dr. Reem Ghandour;** she is the Director of the Officer of the Division of Epidemiology in the Office of Epidemiology and Research. Reem is also a former MCH Epidemiology Outstanding Young Professional Award Winner. Dr. Ghandour will give an overview of the redesign of the survey and present the latest information from the ongoing National Pretest.

Our second presenter will be **Dr. Christina Bethell,** Director of the Child and Adolescent Health Measurement Initiative and a Professor at Johns Hopkins. She is also a former Maternal and Child Health Epidemiology Award winner for Outstanding Leadership. And she'll introduce the Data Resource Center resources that can help optimize the use of existing National Survey of Children's Health data, as well as resources and materials that address the new Title V Block Grant National Outcomes and Performance Measures. I'll now turn the program over to our moderator, Sarah.

Sarah Lifsey, MPP
Altarum Institute

[slide 3] Thank you. First, I'd like to welcome our presenters and everyone who is in the audience today; thank you for joining us. Before we begin our presentations, I just have some brief technical guidance for everybody. First I'd like to call your attention to the DataSpeak website, which we hope you'll visit after today's program. On the website, you'll find archives of all the DataSpeak programs going back to 2000, and the slide on your screen right now shows some of the most recent programs that are available and the address you can use to access them.

[slide 4] I would also like to point out that you are able to download today's PowerPoint presentations and additional resources directly from the screen that you are seeing right now. Once you are finished, you may click the continue button to proceed with the presentation.

Now I would like to turn to our first presenter, Dr. Reem Ghandour.

Redesign of the National Survey of Children's Health

Reem Ghandour, DrPH, MPA – Director, Division of Epidemiology in the Office of Epidemiology and Research – Maternal and Child Health Bureau

[slide 5] Thank you so much Sarah and Michael and thanks to all of you for joining us today. [slide 6] As mentioned, the focus of my talk is going to be the redesign of the National Survey and so to that end I'm going to try to cover the following 3 topics during our time together. First, while we know that many of you are probably very familiar with the National Survey of Children's Health and its sister survey, the National Survey of Children with Special Health Care Needs, I will take a few moments to talk about the history and the uses of the surveys because I think where we've been is vitally important to understanding some of the choices that we've made in crafting the next generation of the survey.

Second, I will spend a significant amount of time talking about the redesign process, the goals that we had for the redesign, how we've tackled the process, and then I'll also spend a little bit of time talking about some of the content changes, because I suspect that is probably one of the areas where folks had the most questions. And then finally, I'll wrap up with a discussion of some of our efforts to refine and test the redesigned survey now that we've made these changes. And to that end, I will be presenting results from our cognitive testing process, our mode effects experimentation, and then I'll try to provide a little bit of information about our pretest process, which is currently underway.

[slide 7] So let me start with a brief overview of the National Surveys, and just as a reminder, there are in fact 2 national surveys. [slide 8] So the first is the National Survey of Children's Health, which was fielded in 2003, 2007 and then 2011 and 12 most recently. And the purpose of the survey, as I think most of you know, was to produce both national and state level estimates of a wide variety of child health indicators.

The second survey is the National Survey of Children with Special Health Care Needs, and this was actually the very first survey that we fielded in 2001. And the purpose of this survey was to provide both national- and state-level estimates of the prevalence and impact of special health care needs on children and their families.

So while these were two different surveys that in many senses targeted different populations and had different goals, they did have some common elements. They were historically directed and funded by the Bureau and fielded by the National Center for Health Statistics as a module of the state- and local-area integrated telephone survey. So these were telephone surveys that were primarily landline-based telephone surveys in the first 2 years of each survey and then also included cell phone samples in the

last year of each survey. Both surveys produced national and state-level estimates, which is a defining feature of these surveys. And all data are collected from parents and caregivers.

[slide 9] And as many of you know, data from both surveys have been used for a variety of purposes. So first and foremost, they have been used for the needs assessments and annual funding applications for our Title V Maternal and Child Health Services Block Grant Program. And I think as a corollary, there are many states that have also used these data to help with their planning and program development around a variety of child health initiatives.

These data are also used for federal policy and program development, most notably Healthy People 2010 and 2020, and in fact, these data are used for 15 objectives in the 2020 Initiative. And then finally, a significant portion of these data have been used in scientific research; I suspect many of your on the phone have used these for your own work.

[slide 10] The next couple of slides just illustrate some of what I just spoke to. So for example, data from the previous National Survey of Children with Special Health Care Needs served as the data source for 5 National Performance Measures for the Title V Block Grant, and that number will actually grow to 18 under the transformed Title V Performance Measurement system. You can see those new measures on the right side of your screen.

[slide 11] These data have been used for a variety of original research initiatives on topics ranging from specific conditions like ADHD and Autism, to systems-level indicators such as under-insurance and medical homes, to life course measures such as adverse childhood experiences, and then finally state-level analyses as well. [slide 12] And importantly, these data have been publically available for users from all backgrounds through our Data Resource Center, which has been expertly managed and developed by Dr. Christy Bethell, our next speaker and her staff.

And this has served as a one-stop-shop providing everything from quick access to a national prevalence estimate on a specific condition to in-depth translational analyses that really contextualize such estimates.

So taken together, I think you can see that these data have historically had a tremendous reach in the MCH field, and now our task, with the redesign, is to ensure that this reach is not only preserved, but hopefully extended as well.

[slide 13] So let me turn now to the redesign. [slide 14] I like to use this image because I think it is the best way to describe why we had to initiate a redesign of the National Survey, and I do want to give credit where credit is due. This is produced by Dr. Stephen Blumberg, who's been a longtime supporter of the survey. What I like about this image is that you can put this one up and even folks without any background in survey methods or research per se, will start to nod their heads, because I think it's pretty clear from this image why we can no longer expect to use a landline telephone system in order to collect representative and high-quality data on children and children's health. And as you can see here, over half of children live on those wireless-only households as of 2014, and that number is only going up with time.

And our experience I think importantly in the last decade, also suggests that just because you add a cell phone sample doesn't necessarily provide the silver bullet that you might want to address this kind of problem. So we found that just adding a cell phone sample was not particularly efficient; 1 because it's expensive to call cell phones and 2, because even if you call a cell phone with a designated area code, you can't be sure that you're actually talking to someone in that geographic region.

So with that in mind, the purpose of our redesign was really 3-fold. First, we had to shift the survey sampling frame from landline and telephone numbers to household addresses. Second, we wanted to take this as an opportunity to combine the 2 national surveys into a single instrument, because we found that there really was a lot of overlapping content, and we felt like it would be more efficient and effective to field a single survey.

And then finally, we wanted to provide more timely data. I think many of us are used to hearing phrases like, "immediate data" or "real-time data," and I think it's probably unlikely that any of us can expect that a survey of this scope and nature could ever provide real-time data per se, but I think we can certainly get much better at providing more timely data.

[slide 15] So this slide is designed to give you a sense of just some of the processes that we've gone through to redesign the survey. I'm not going to read through each one of these steps, but in general, we really did 3 things. The first is that we tried to learn from experts, folks who had experience doing this kind of transition. So, we talked to folks at the Department of Education who have transitioned the National Household Education Survey. We talked to folks like Don Drummond, who have a significant amount of experience in designing and developing surveys for different modalities, and we certainly tapped into longtime advocates of the survey like Stephen Blumberg, who have spent a lot of time thinking about the next generation of health surveys.

We also used our technical expert panel very heavily to help us think about the kind of content decisions that needed to be made. We recognized that there was a lot of valuable content in both surveys and that merging them would potentially result in some difficult cuts, but we wanted to work with the best and the brightest in the field to help us think through some of those difficult decisions. And finally, we utilized some contract mechanisms. We worked with NORC to conduct some qualitative assessments of redesigned surveys, and we now have an interagency agreement with the Census Bureau to carry out a full-scale national pretest.

[slide 16] One thing I would say about all of those processes is though I tried to present them as sort of a linear experience on the slide, in fact, it was a very iterative process. And so, ultimately resulting in some key decisions that you can see here on this next slide, first we decided to work with a single combined survey that will be fielded annually starting in 2017. While we expect new national estimates to be available every year, it's very likely that state-level estimates will be available every other year; I should say new state-level estimates will be available every other year. We will be using an address-based sampling frame, and the vast majority of interviews will be conducted in a self-directed way, meaning individuals will complete either a paper and pencil or a web-based interview with very limited telephone follow up as necessary.

[slide 17] In terms of our timeline of activities, I've highlighted where we are now in red; we are currently have a survey pretest, a national pretest underway that will be going through next winter with the survey pretest data being available in the spring for preliminary analyses internally. Ultimately, we'll be fielding the production survey in 2016 with the first public release of data in late 2017.

[slide 18] I'm just going to spend a few minutes talking about some of the content changes. [slide 19] If you have specific questions about a particular content area or particular item, I'm more than happy to try to address that during the Q&A session, or to talk about it offline. But what I wanted to do here was just to sort of remind you about the breadth of the survey content, and then to walk through some of the criteria that we use in thinking about whether or not we would be retaining content.

So first, as a reminder, even though we talk about a single survey, the National Survey of Children's Health, it is, in fact, actually 3 separate, age-specific modules; 1 for 0 to 5 year olds, 1 for 6 to 11 year olds and 1 for 12 to 17 year olds. Each of these age-specific modules does contain content in these 8 core areas that you see on your screen, but there is also age-specific content where appropriate. So, for the 0 to 5 year olds, we have added a significant amount of content around being healthy and ready to learn and for the 12 to 17 year olds, we have retained content on healthcare transition planning.

[slide 20] In general, where we had to make changes for the content, those changes were made based on the sort of following 6…it lists 5 here, but there are really 6 criteria or reasons behind our change. First, we often had to make some changes based on what was expected of us from OMB or other federal policies and programs and a key example of this is the addition of what are called the ACS-6 disability items. These are required of all health-related surveys and so we've added these in as appropriate to each age module which means that we'll now be able to report on both special health care need status as well as disability status.

Second, we made changes to the content based on new or expanded understanding of a particular issue or topic. So for example, thanks to our friends at the CDC, we've added items around ADHD treatment, which focus on both behavioral treatment as well as medication treatment as separate concepts. Three, we had to make a number of hard decisions because we were combining content from 2 surveys, so that severely limited our space.

Four, we found that the transition from a telephone interview survey to one which would be self-administered actually required a fair bit of thinking in order to remove some of those tricky situations where respondents were really dependent upon the interviewer to help them navigate the questions. So you'll certainly see changes around the introductory language and the navigating language in the survey in order to make it easier for respondents to work their way through.

Five, we made changes in order to really focus that very limited space that we had on Bureau priorities, so you'll see a very close tie to those 18 performance measures and outcome measures for the Title V Block Grant. And 6, we added new content that reflected some emerging priorities, and specifically, the big addition was content around school readiness or healthy and ready to learn.

[slide 21] So let me turn now to some of the results from our qualitative assessment work and then the pretest. [slide 22] We contracted with NORC to conduct cognitive and usability testing in order to identify issues that might be stemming from the shift in mode. So in other words, we needed to know whether or not respondents understood the questions when they were self-administering the questionnaire. NORC conducted 64 1-on-1 interviews with adults who were parents of children age 0 to 17 in both English and Spanish and importantly, one quarter of the interviews were conducted with parents regarding the children who had special health care needs.

[slide 23] For the most part and this was good news I think for all of us, was that there were no major content issues identified through the cognitive testing. There were, however, some lingering difficulties that I think we are going to continue to keep an eye on as we go through the pretest process, I'm not going to read what's on the slide, but I think just highlight 2 here for you.

One was that we found that some respondents struggled when you were applying a uniform question structure or response structure to a wide range of conditions; so applying the same question approach to conditions that might be episodic or mild as we did to those that might be lifetime diagnoses or highly debilitating. And I think we also saw some issues around the skip patterns, so we clearly still have some work to do around the navigation of the survey, given how complex some of our questions are.

[slide 24] We also worked with NORC to conduct a mode effects experiment in order to determine whether item responses or response rates varied by mode of survey administration. So this utilized an equal probability sample of approximately 34,000 records of households that were 1— associated with both an address and a phone number, and 2—likely to contain a child under the age of 18. From this sample then of 34,000, each record was randomly assigned to one of the 3 treatment modes mail, web or telephone.

[slide 25] This slide provides a snapshot of the results from this experimentation. I'm happy to provide more detail after the presentation. But I think at the end of the day it's sort of a glass half full, half empty picture with the major take-home points being 1—we are still, at least in this test, struggling with response rates. So interview completion rates were reasonable, but the overall response rates were still very low, and as part of that picture, we discovered that web is not quite the silver bullet that we thought it was going to be. So I think there's potential there, but we still have to really think about the best way to maximize the use of web.

On the more positive side, we found that the questionnaire length did not appear to be a problem for either the web- or paper-based questionnaire. And I think this was an important finding for us, because we were, I think, fearful that having combined 2 surveys, having a lot of extra content in the survey, that we were ultimately going to end up with an instrument that would be just simply too burdensome for folks to complete. So even removing a third of the items for a shortened questionnaire didn't ultimately make that much of a difference. And I think that was an important finding for us through this process.

[slide 26] Finally, we also asked NORC to test a couple of key indicators; I've highlighted some here. Overall the take-home message was that there wasn't a lot of variation by mode, but there were certainly some differences that were statistically significant. What's probably most important to note is

that there was no pattern observed where one mode produced estimates associated with better or worse health or access; so, there are differences occurring, but there's not a pattern that we can really rely on in terms of working with a particular mode. One thing I would highlight here, is that there was actually no difference in the prevalence of special health care need by mode.

We also had NORC conduct some adjusted analyses here just to see if sociodemographic differences in the nature of the demographics of the folks who actually completed the survey by modes made a difference. And ultimately, we still found that there were differences for some of these key indicators. So ultimately, we are going to be dealing with some differences by mode, we expect, and this is something we're really going to have to look for in the pretest results, to get a better understanding of.

[slide 27] So speaking of the pretest, [slide 28] let me wrap up with just a few remarks about the pretest study design. We launched the pretest June 10, this summer. We have a sample of 16,000 households that was drawn from Census' own Center for Administrative Records Research and Applications. Those cases are allocated proportionately across 50 states and the District of Columbia, and you can see that they're equally split into 2 arms, one is a mail push or sort of a standard you've received a screener, you send the screener back, and then you get a topical interview. And the other is what we call the web push where you receive a letter inviting you to complete the survey online. If you go online, you will complete the screener and then immediately drop into an appropriate topical interview online.

Again, we started on June 10; as of this week we had about 70% of all screeners completed for both the web and the paper survey arms of the test. So we have currently 770 completed topical surveys by paper and 1,371 completed topical interviews by web. [slide 29] And we believe that the design that I just showed you does really reflect the primary goal of our pretest which is to do a large-scale test of the operations; so does this survey work in the field?

Some of the questions that we're going to continue to focus on are opportunities to really maximize the response rates, and the best ways to use web, if we're going to use it, which we are likely to use. We're also going to be looking at what adjustments might be needed to determine the best way to get the response rates for key constituencies like children with special health care needs, and then representative samples for our state-level estimates that are needed. And then we'll continue to look at the questionnaire content and any adjustments that might be needed to address some of those tricky skip patterns, and those kinds of things that we saw in the cognitive testing, as well as some of the mode effects differences that we saw under NORC's work.

In terms of our next steps, it's a little crazy to say this, but even though we have essentially just started the pretest, we are already planning for production. So there are a couple of interesting ideas that we're working with Census on now including some proposals for an incentive experiment to control cost and looking at which follow-up procedures for both low and high internet areas—again looking for ways to really maximize the use of the internet. And then finally we're looking for some innovations to utilize supplementary administrative data, whether it's from the Social Security Administration, SSI, or even the IRS, to improve our targeting of households with families and children.

[slide 30] I do want to just take a second to acknowledge the fact that this was truly a team effort; none of this could have gotten done without a lot of time and energy from folks here at the Bureau and our leadership, but also our technical expert panel, all of our federal partners who have contributed time and money to this effort—NORC and then finally CAHMI and the Data Resource Center. Christy and her team have contributed so much to the survey over the years, and now they are continuing to play an integral role in the redesign process. [slide 31] So I want to close there, and I'm happy to answer questions both after the program and then certainly during our Q&A session today.

Sarah Lifsey
Great. Well thank you so much. Up next, I'd like to turn to our next speaker, Dr. Christina Bethell.

Redesign of the National Survey of Children's Health

Christina Bethell, PhD, MPH, MBA – Professor and Director, The Child and Adolescent Health Measurement Initiative – Johns Hopkins Bloomberg School of Public Health

[slide 32] Great, thank you Sarah and everyone on the call. I'm going to pick up where Reem left off, and talk a little bit about not only resources that are available for you to use the current National Survey of Children's Health, which has tremendous relevance and value for you right now, but also some of what might be coming up, what's coming up for us to support the use of the new data as it's coming down the pike.

[slide 33] So my goals today are first of all to continue to inspire you to access and integrate already available data from the National Survey of Children's Health and the resources that are here at the Data Resource Center for Child and Adolescent Health to advance MCH outcomes and performance, which is a major focus for many of you on the call today. And also for those of you who aren't already familiar with the Data Resource Center, to empower you to first access the Child Health Data Interactive Data Query and other resources available through the Data Resource Center.

I would just challenge you if you listen to the presentation, to discover at least one new idea that you might be able to use the resources from the Data Resource Center to address in your existing partnerships in your state and local areas to advance MCH outcomes and performance. And then again invite you to share obviously today, but in through giving us feedback online, and also through phone calls or any other venue, what your needs and ideas are so that we can further optimize the use of the maternal and child health data to address your priorities, because that is our commitment. Next slide.

[slide 34] So the Data Resource Center for Child and Adolescent Health is supported through the Maternal and Child Health Bureau, and has been since 2003, when we initiated the activity and all the way until now. And our goal is to provide a centralized, user-friendly, and interactive access point to gain microdata and metadata to standardize national-, regional- and state-level findings from national- and state-level surveys such as the National Survey of Children's Health. And as importantly, to use those resources to build a shared knowledge base and capacity for using data and to drive improvements, and also to inspire innovative uses of information to really innovate in advancing and improving maternal and child health, which we have a long way to go still in that goal. Next slide.

[slide 35] So our originating idea for the Data Resource Center was exactly that—to drive systems improvement through the effective use of data. And this is the slide providing some information on the first survey; it was the National Survey of Children with Special Health Care Needs, which is really organized around assistance of care model for children with special health care needs. And the work was to develop measures and get them collected and out to states and others, and it's a very successful model, and so we'll continue to work to advance performance in the new Title V Block Grant Performance Outcomes Measures that are in the field today. Next slide.

[slide 36] And our originating theory of action was that in order to drive system change, we really need to be able to learn. And we learn through being able to compare against groups with variation, across states, across groups within our state, about how what we're doing in policy and practice is making a difference. And all of that learning and comparing requires some way to standardize measures so that we can have a conversation about what it is we're talking about. So, the data from the National Survey of Children's Health and other data available provide a standardized starting point for having a conversation. Next slide.

[slide 37] So with that, the scope of the Data Resource Center really is a 3-legged stool. This slide looks slightly different than it does on the original slide, sorry for that, but our 3-legged stool in the Data Resource Center for what we're up to is first of all to work with the Bureau and all the partners that Reem mentioned, to help identify transformative goals for child health and measures that can discern measures that…and develop the data that can help drive actionable use of data in the field. And then to use the data that's developed through the National Survey of Children's Health and measured to inspire and inform transformational partnerships in the field that can then innovate and act to hopefully meet those goals. So that's really different parts of our activities focus on this.

Most of you, next slide, [slide 38] are familiar with the frontward facing view of the Data Resource Center, which is our website. And this is a view of the website, childhealthdata.org. I welcome you to visit it now if you are online. We're in the process of a redesign of the look and feel of this website, but here it is right now.

And the…next slide [slide 39] and the types of things that the Data Resource Center website and all the resources can help you with is really advancing competencies across at least 12 key skills that are outlined in the Maternal and Child Health Leadership Competencies as they relate to data. And I'm not going to read through all of these, but for those of you who are in MCH Programs, you're probably familiar with these, and there's something available in the Data Resource Center bag of tricks that can help support you in developing competencies and achieving the various goals in this list of 12 key leadership skills. Next slide.

[slide 40] And the other major goal is to really focus on helping advance your state priorities. This is a list of priorities that were identified through the last Block Grant cycle, and you can see from this table, if you look over where the exes are, outline data that is available through the Data Resource Center website that relate to the various outcomes and goals that…agencies had identified as priorities in the

last Block Grant cycle. So a lot of the information that you need is available on the website right now, even as we're moving toward a new set of specific outcomes and performance measures. Next slide.

[slide 41] The National Survey of Children's Health right now, the 2011-12 includes information across a variety of content areas, and I'm just going to read them briefly for those of you who aren't familiar; physical and dental health, emotional and mental health, health insurance coverage and adequacy, health care access and quality, immunity and school activities, family health and activities and neighborhood safety and support. And one of the things that we do to help you optimize the use of this data, in the next slide, [slide 42] is organize it around different program strategies.

So here's just an example of a very recent strategy is organizing the data around the new national performance measures and the new national outcome measures. So there's a lot of data right now on a number of the outcomes and performance measures and you can go online and access the data according to this strategic frame. There are other strategic frames that we also use; one is Healthy People 2020, which Reem mentioned, and if you go to the next slide, [slide 43] there's also measures that speak to what is prioritized in the Accountable Care Act and in CHIPRA legislation as categories of measures. So there are different ways to organize the information; we try to anticipate what that is for you so that you can fast-track to finding information according to the strategic program priorities that you have and the way that you want to be looking at it. And the next slide.

[slide 44] Another feature is to make sure you have some information on where these measures stand in terms of whether they're endorsed nationally. We have been able to, in recent years, gain endorsement through the National Quality Forum on a number of measures through the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs. And for those of you working with Medicaid agencies or with payers or health plans in your strategies to improve maternal and child health, sometimes that really matters and knowing that could be important to making your case for why the kinds of data and information and measurement strategies available through the National Survey of Children's Health are, in fact, relevant to that larger set of partners who do want to measure according to national guidelines from the NQF. Next slide.

[slide 45] And I'll just close this section by saying that improvement partnerships and data-driven partnerships are the way that we're going to really be able to improve maternal and child health outcomes. And there are a lot of activities going on right now to develop these partnerships, all of which really speak to a transformation and how we think about organizing systems, coordinating systems and every single piece of the transformation process, this is just one example of 4 phases outlined by John Kotter on transformation, requires data. So establishing a sense of urgency, getting people on board, creating a guiding partnership, developing a vision and strategy, communicating about that, empowering action and so on—all of these steps require data.

[slide 46] So with that, wanted to just draw your attention, for those of you who are in the midst of thinking about using not only the data that's available today as we wait for the new data, that we do have resources on how to think about using the Data Resource Center resources to organize improvement efforts around the MCH outcomes and performance measures.

[slide 47] There's a 1-pager that outlines a series of steps that you can consider on how to use the data now to both understand your population, assess the current system performance, and examine improvement opportunities according to subgroups of children in your space. So those are 3 clear things that can be done now using the Data Resource Center.

[slide 48] In addition, to select priorities using data, you might be able to see what issues are most salient to the most people in your population and in your state; that may be one way to look at it, but there are a lot of other ways as well. To set targets, because you can look at data across all states and across subgroups across all states, you can start to get a sense of where your state might be according to other states and give you some targets to move toward. And that's an important thing for improvement is having a sense of where there is to go, and without national norms of a formal kind, this is a resource for you to consider.

Identifying promising improvement models. There's an evidence base that needs to be tapped into and a very formal process for that, but there's also information here where you'll see a tremendous amount of variation across states on similar performance metrics. And it raises the question of, what are other states doing that you might consider, and maybe calling them and getting in touch with them about what strategies they might be using. And then finally, to monitor progress; the good news about the National Survey of Children's Health now is that it's meant to be collected every year going forward and so for the metrics, where it's possible to be reported every year, this will give you a strong basis for monitoring progress.

[slide 49] So now I'm going to take the rest of this time to give you a walk-through of the data website and the resources and features that are available there. For those of you who have not had a chance to go through it, you're welcome to join me online if you'd like, otherwise I'm going to just do some screen shots to walk you through a couple of ways to start accessing the information.

So the DRC features available now are fast-track resources to learn about the surveys. There's a lot of complexity in these surveys and the methods documents and the survey documents are in the hundreds of pages typically, so we do a lot of work to create simple-to-read and understand. Learn about the survey materials that can fast track you to finding out what…how the data was collected, how the survey items were asked, how they're scored and what the data means.

The second main feature is to search and compare findings, micro-findings at the national, regional and state level for a number of child subgroups; just listing a few here age, race, ethnicity, special need status and so on. The next feature is to access topically-focused data snapshots and profiles, and we bring together a number of indicators to formulate a picture performance say around medical home or around children with special health care needs systems of care and so on. And then finally to get expert help, we're here literally 24-hours-a-day to answer your questions online by asking a question in the ask a question feature.

[slide 50] So the featured data sets at this point, if you're on the website, you can see what the list of featured data sets are by clicking on "Learn about the Survey" or by going to "Browse the Data." And you'll see different options for how you can access the data. On the "Learn About the Survey" with the

National Survey of Children's Health, all of the years for which it's been collected. The National Survey of Children with Special Health Care Needs, and even though it's not going to be collected again, of course, as Reem said, a lot of the content is included in the future survey, but this is data that's still very powerful and relevant and I would argue, underused.

There's also National Survey of Children with Special Health Care Needs follow up survey done for children experiencing autism spectrum disorders and the National Health Interview Survey data, the child and family files, we have empowered you to be able to access that data, as well as Complementary and Alternative Medicine Survey supplement from the NHIS for children and youth. So those are the data sets that are available now on the Data Resource Center.

[slide 51] And I'm going to just take you through a couple of different ways to think about accessing the data. Option number 1 is what I call the 360-tour, so if you're not as familiar with how to use the query tool to access microdata, this is a really easy way for you to begin. First of all, going over to the "Data at a Glance" where there's a US map, and clicking on "Browse Data Snapshots" is one way to begin. [slide 52] When you do that, you just first select your state—[slide 53] and we're going to select a state—and you can also then click on what type of profile you want to look at. This is just a general overall profile of data available through the National Survey of Children's Health 2011-12, and it gives you a broad view of what's available.

[slide 54] So when you click on that, you can see the major categories of information that are available through that survey, and then hone in on one that you're interested in. And when you click on that, on this we're picking Insurance Coverage, Consistency of Insurance Coverage, [slide 55] it actually will take you into the heart of the query which is going item-by-item, where you can look in greater depth about what's going on in your state in that area. So here we have the District of Columbia, looking at Health Insurance, Consistency of Health Insurance Coverage comparing to the nation. You can also choose other areas to compare to. You get both a graphical and tabular set of findings that also speak to confidence intervals and raw numbers and weighted estimates for your state.

[slide 56] At this point, you can start looking at subgroups iteratively, and in this case we're going to pick Type of Insurance as a subgroup. [slide 57] So you want to look at Consistency of Insurance by Type of Insurance, and you are seeing, you know that there is some variation, at least in the District of Columbia, in Consistency of Insurance by Type. [slide 58] If you're interested at this point on where your state ranks across all states, you can just go back up to "Compare States" and pick the "All States" option [slide 59] which will take you to a view like this. You can also, here, look at subgroups at the All States view, but right now we're just looking at it overall.

And it gives you a sense of, you know if you click on the columns, you can sort the data either by currently insured or not insured the full year. But you can rank in either direction, top to bottom, bottom to top or by response options. You start to examine where your state falls if that's of interest and value to you. [slide 60] And then, of course, you can go back in here, right back into the query and continue where you left off, and continue to pick new topics, areas, and this is sort of an interactive way to relate to the data.

You can also save your results into your own "Briefcase" if you would like that feature, and also, over here with the data tools, print them get a downloaded PDF, e-mail the page to a friend or colleague, share the page on Facebook, and make a comment, or tweet the page. So this is a way for you to actively use data in the field to educate those that you're…

[slide 61] The full search option is where you know you want to go right in, you know what you want, you know the data set you want, and you're interested in going right into it. So here you just search by survey and topic. [slide 62] So you pick a survey, National Survey of Children's Health, you pick a topical area, and this is where you get the option to choose whether you're going to look at overall state profile, or Healthy People 2020, or what kind of categorization framing you want to use for selecting data.

And here we're just picking National Survey of Children's Health [slide 63] and health status and then the topics that are available by health status come up, and you maybe pick Missed School Days in this case, in this example. [slide 64] And again you go back into the query where you can begin to iteratively search by subgroup, compare to other areas, look at all states, go back in and continue the process at that point.

[slide 65] So I'm going to end by just letting you know that we have technical assistance that we provide across a range of factors. And we often get a lot of questions that are very simple like, "where do I find this?" or "this is what I think this means, am I right?" Also things about "how do I access the data set?" [slide 66] We do provide downloadable cleaned and labeled survey data sets with pre-constructed indicators and additional variables which can fast-track your use of the data in research.

And we have thousands and thousands of people who do that, so don't be shy. You can also learn about effective ways to use the data in our data in action, putting data into action component of the website, which will be really wanting to focus on how Title V systems of care are advancing MCH outcomes and performance measures in our "Data in Action" features going forward. So if you have anything you want to share and have featured as a "Data in Action" example, please send it to us, and we like to do stories on that.

And then sign up for the e-updates. We don't do a lot of e-updates, but we hope to do more targeted updates on topical areas. So if you're interested in certain topical areas, like children with special health care needs, or medical home, or adverse childhood experiences, please let us know, and we will be able to do more targeted outreach where we don't send to everyone in our email database, but to those who have claimed that they are interested. And you're going to get a chance to do that also online in the redesign. "Data in Action" [slide 67] This is a picture of a little bit of the resources that are available for using data.

[slide 68] So just to recap, we need data for a lot of reasons both to educate ourselves and check assumptions and clarify definitions and measurement of priority topics. And I find this to be very critical, because often groups come together and don't check out their assumptions about data, or make sure they're using standardized ways of talking about data, and the Data Resource Center can really help with that. Certainly could document needs and system performance, inform and activate your partnerships,

educate program leaders and policymakers who often need to be brought along to focus on children and maternal and child health, and also in grant writing, and research, and paper development.

[slide 69] Emerging resources and updates; we are in the midst of a website redesign, as I mentioned to you, where we'll be having a new Title V portal, actually I want to show that to you. [slide 70] And we're welcoming anybody online who wants to be a part of our group to discuss how we can optimize the use of the portal for your purposes, let us know. [slide 71] We also have state-specific pages where there'll be a page for every single state where features and data and materials specific to your state can be uploaded and featured.

Also an MCH measures portal that starts to look not just at the data that's in the Data Resource Center, but across the field, where MCH measures are at large and how they compare. There's an autism portal that features the Pathways data. We already have medical home, children with special health care needs portals and those will be there. In addition, you saw earlier a map that features the Title V Block Grant measures as they are measured in the 2011-12 National Survey of Children's Health. You will be able to query and gain access to that data very soon.

And again, additional data from the National Health Interview Survey will be continued to be uploaded as we work to already... Reem was saying how she's already thinking about, and everybody's already thinking about how to collect the data, well, we're already thinking about how to score, present, disseminate and support the use of the data because there are so many steps involved. So we're already busy thinking about that and are looking forward to the 2016-17 data release.

[slide 72] So with that, I will end and just with a few pictures of [slide 73] the new look and feel for the upcoming data website [slide 74] and the Title V portal. And I, like Reem, welcome any questions in our open questions here today as well as through [slide 75] the website, info@cahmi.org, you can ask a question, or e-mail me directly.

Questions and Answers

Sarah Lifsey
[slide 76] All right, great; thank you so much, and thanks again to both of our presenters today. It's been a very engaging program, and we already have some questions coming in. I will go ahead and start with some of the online questions that have come in. The first question I have is from Sherry who wants to know:

How will the data made available to users such as through data ferret or through CAHMI, and how much user access will there be to cleaned and validated raw data, and when can users expect access to that kind of data?

> *(Reem Ghandour)* So I assume—this is Reem—I assume we're talking about the redesigned National Survey of Children's Health Data. In terms of the first public release of the data, we are hoping and we are working very closely with Christy and her team to ensure that similar access as has been available in previous years to cleaned data sets will be available probably sometime in 2017. It's

really hard for me to say much more than that this point, but we anticipate having all of the data completed and ready for use in the Title V Block Grant applications in late spring of 2017 with sort of the larger public release later in the year.

And certainly as we learn more about our timeline, we're going to make that available. Some of that is going to depend on what proportion of the data are ultimately collected online through the web push rather than in the paper-based surveys. If we are able to really maximize the web-based component of the survey, we may be able to get those data out sooner, but it's still going to be a work in progress to get everything cleaned and coded appropriately as folks are used to receiving it.

Sarah Lifsey
Okay, great. The second question I have is from a different Sherry, actually, who asks:

[I'm] curious—what the thoughts issues were related to expanding the survey to families living in territories?

(Reem Ghandour) That's a great question, and one that actually Christy and I have talked about. The goal is, I mean, I think we are talking about opportunities to do that in the out years; unfortunately, the cost associated with transitioning the survey and moving to a totally different mode precluded us from doing that with this initial 2017 fielding of the survey, that it's something that we are committed to trying to do in the out years and I think that's a conversation we're going to be continuing to have. It is a priority for the Bureau.

Sarah Lifsey
Okay, good.

(Christina Bethell) Speaking of which, we do have, just for those who may be looking for it, the Virgin Islands is will be available on the Data Resource Center. It hadn't been on the past for a variety of reasons, but it will be now. So that's one thing I wanted to add since somebody brought it up.

Sarah Lifsey
Great. I don't think we have any phone questions as of yet, so I'll continue with the online questions. The next question we have is from Don who asks:

Was there any discussion about providing annual state estimates using rolling averages such as the American Community Survey does?

(Reem Ghandour) Yes absolutely. I think that's something that we are going to consider doing. So I tried to keep my slides sort of clean for the sake of presentation and discussion, but yes, I think we are going to look into every possible way to get states usable data that will help them in their planning and program development, so yes.

Sarah Lifsey
The next question I have for either speaker is from Ava who asks:

Can you talk more about the availability of sub-state estimates? This is a real need.

(Christina Bethell) I can speak to that if that's something…Reem, did you want to say anything or?

(Reem Ghandour) No, no, please.

(Christina Bethell) Okay, great. Well, Dr. Kogan's on the line, and we've been talking for a number of years about optimizing the use of the National Survey of Children's Health and all the data for local areas using synthetic estimation, which is pretty widely-used in a lot of different venues, even in economics and education, and other important areas. So we wanted to apply synthetic estimation models to be able to get data at the local level. And we have proceeded in the last several years in both supporting local areas, if they have their denominators, we have numerators, and there's a math equation that can be used to try to translate the data into local synthetic estimates. And so we do have a 2-pager online that begins that process and welcome a lot of questions about that.

In addition to that, we have collected the data from the Census Bureau on areas…to all counties in the US and cities under…that have at least 70,000 cases and are in the process of developing a local - area estimator function on the Data Resource Center as possible. So that is in the works, and we've been working with a number of technical assistance activities to get data earlier than we can get it online through a query, as we're able to. So, for those of you who are interested in that, please let us know, and we will respond to you. So, I don't know if Michael wants to say any more about that because he's given a whole workshop on that in the past.

(Michael Kogan) No, you covered it well Christy, thanks.

(Christina Bethell) Great, thank you.

Sarah Lifsey
Great. The next question, which is kind of related, is from Diviya:

How has the new survey addressed racial stratification for states with American Indian population as the secondary population for Meaningful Use?

(Reem Ghandour) That's a little bit of a tough question for me to answer; I can say that at the moment, what we are working with at Census, is we're using their standard racial and ethnic categories in the survey instrument, and so we've had to provide some of that. But it's a little hard for me to tell you how ultimately we're going to make that adjustment when the data are publicly available. I mean, that was a decision, and I'm going to defer also to Christy and Michael who were more central to those decisions with the previous surveys.

I think we're going to have to make some slightly different decisions, because the sampling is going to be different this time around, but we're going to everything we can to make those estimates available. So I don't know, Christy and Michael, if you have any thoughts about how it could look different going forward? I just don't think we have enough information right now.

(Christina Bethell) Yeah.

(Michael Kogan) Right, I would agree, Reem, I think it's really hard to say at this time, until we get more information from the pretest. I mean, I know we'd like to have estimates for as many states as possible.

(Christina Bethell) Right.

(Michael Kogan) We're just going to have to see.

Sarah Lifsey

Okay, great. I think we've got time for one more question, and this is a question from Dorothy.

What is the targeted error rate for the state-level estimates with the new sampling scheme? And is that the target error rate as well for the Survey for Children with Special Health Care Needs?

(Reem Ghandour) I don't have an answer for that right now; we're still working on the sampling plan for production, and we have a number of different constraints and criteria that we're going to be working with to do that, so unfortunately I can't get into that right now. I'm hoping we'll have more information about that later in the fall.

Adjourn

Sarah Lifsey

[slide 77] Okay, great. I think that is all the time we have today for questions and answers. If you asked a question using the online form that we did not address, we will address those with questions with answers from our speakers and will post those, in writing, along with the program archive. And if you think of any more questions, you can submit those to us via email through the next week using the e-mail address you see on your screen there, dataspeak@altarum.org.

[slide 78] So finally, before you log out, we'd really appreciate you taking a moment to provide us with feedback on today's program. It's really important to us that we have your input on this session as well as your recommendations for future program topics. This is a very short survey. If you click on the evaluation link on your screen now, the survey will open up in a new window.

And lastly, I'd like to thank our two speakers for joining us today and for providing such great information. Today's program is now complete. Thanks to everyone in the audience for joining us, and have a great afternoon.

About DataSpeak

The MCHB's DataSpeak webinar series is dedicated to the goal of helping MCH practitioners on the Federal, State, and local levels to improve their capacity to gather, analyze, and use data for planning and policymaking. DataSpeak is funded by the MCHB's Office of Epidemiology and Research.

October 2015