DataSpeak: Orientation to the State Systems Development Initiative Minimum/Core Dataset Implementation Guide
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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 State Systems Development Initiative (SSDI), Minimum/Core Dataset Implementation Guide, which is perhaps the longest title in the history of the DataSpeak series? I'm Michael Kogan, and I'm the Director of the Office of Epidemiology and Research at the Maternal and Child Health Bureau (MCHB), which is the sponsor of the DataSpeak series.

The purpose of today's DataSpeak is to provide an orientation to the newly-developed Minimum/Core Dataset Implementation Guide. This guide is intended to help states in applying uniform standards to the development of minimum core indicators. These indicators evolve from the need to improve standardization of data in maternal and child health with the consensus-based common set of reporting measures, definitions and data elements.

The minimum dataset includes indicators that all states should be able to report, such as that infant mortality rate. The core dataset includes measures that involve data linkages and nonstandard datasets, such as safe sleep indicators. The guidance elements have been pilot-tested, and the results of that test will also be presented today.

Today's discussion is a general overview, and a more in-depth presentation is scheduled for the AMCHP [Association of Maternal & Child Health Programs] conference in January 2016, here in Washington DC. We are excited to have with us today 2 speakers to discuss the implementation guide.

[slide 2] Our first presenter today will be **Dr. Mary Kay Kenney.** She is a health statistician with the Office of Epidemiology and Research in the MCHB. Dr. Kenney will give an overview of the Minimum/Core Dataset and implementation Guide, including its development and processes.

Our second presenter will be **Ms. Dina Dickerson,** a senior informaticist with over 4 decades of experience in health information science and technology realm. Miss Dickerson was a participant in the Core Dataset pilot and will share a user's perspectives on the tools. I will now turn the program over to our moderator, Sarah Lifsey. Sarah?

Sarah Lifsey, MPP
Altarum Institute

[slide 3] Thank you. First, I would like to welcome our presenters and everyone who is in the audience today—thank you all for joining us. Before we begin our presentation, I have some brief technical guidance for everyone.

First, I would like to call your attention to the [DataSpeak website](#) which we hope you will visit after today's program. On the website, you will 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.

[slide 4] I would also like to point out that you are able to download [today's PowerPoint presentations](#) [download the PDF from the [archive web page of this DataSpeak](#)] directly from the screen that you are seeing right now. On the left, click on the slide presentation that you are interested in to highlight it; then click save to my computer, and follow the simple instructions on the screen.

So, now I would like to turn to our first speaker, Dr. Mary Kay Kenney.

Transforming the SSDI Grant Program: The Minimum/Core Dataset Explained

Mary Kay Kenney, PhD – US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau

[slide 5] Good afternoon. As was stated by Dr. Kogan, the purpose of this session is primarily to orient users of the SSDI Minimum/Core Dataset Implementation Guide—which is a mouthful—to its purpose and content.

This presentation received a session scheduled for AMCHP in January for those who will actually be using the guide to get a closer look and greater familiarity. And the reason for these sessions is that we would like those who will be responsible for implementing the task to have an idea what to expect and understand that these can be useful tools and learning tools and not just "make work" tools.

[slide 6] The learning objectives for today are that participants will be able to define the purpose of the SSDI Minimum/Core Dataset Implementation Guide, to describe the major components of the guide and the accompanying tools, and to explain how to follow the instructions in the guide to obtain the required data and record that in the accompanying workbook for future reference.

[slide 7] First of all, I would like to talk a bit about the unique relationship between the SSDI Program and the Block Grant. SSDI was established as a funding tool to expand data capacity and infrastructure in the 50 states, DC and the territories. The reason was to ensure that the Title V Programs would have access to policy and program-relevant information and data.

There has been much progress in state data capacity; much has been accomplished through its funding. There are several examples; for instance, expansion of real-time data usage in infant mortality, which is allowing states to be able to detect patterns more quickly and to adjust to emerging trends with the most appropriate and effective tools.

Another example is the use of geographical information systems to help map health data county by county. And the expansion of—very importantly—of data linkage with birth and death records,

Medicaid, WIC, and newborn screening data, just to mention a few of the data bases used in a number of states.

The result is that these are all advances that make our efforts more responsive and focused. They allow us to see trends or relationships across different data types. They provide clues to causes and conditions, and they allow us—importantly—to make evidence-based judgments about the drivers of change which in turn makes it possible for us to tailor our interventions to fit the needs of communities. So much has been accomplished; however it was becoming apparent that a great deal still remained to be done.

[slide 8] With all this in mind, MCHB convened the SSDI Workgroup a few years ago with the purpose in mind of developing ideas for new approaches to SSDI funding and those ideas would specifically grow capacity to fit the greater demands of more complex data systems. The composition of the workgroup was varied; we have state-level staff from MCH programs around the country, we had federal partners, we had academics in the MCH field, we had our partner service organizations and individuals from various divisions around the MCHB.

We had monthly meetings, the main topic of which was—initially at least—what was working well and what were the perceived gaps in the functioning across MCH departments. Some things were working very well. The states very much appreciated the funding that provided basic infrastructure for states to do their epi work.

States used their money in many different ways. For some states, it made the difference between having an epidemiologist or a program analyst at least part-time or not having that help. Others could do more advanced things, because they may have more state internal resources to do things like linking data or using funds to support upgrades to their systems.

However, the group concluded there were gaps in 2 main areas. And the first, there was an unevenness in capacity across the states. Some states were working at relatively advanced levels, and other states with fewer resources were still struggling at much more basic levels. And secondly, there was a lack of standardization that impeded states when it came to collaborating.

[slide 9] So the workgroup developed a charter to define its purpose and focus—its goals—and they developed objectives for various products and activities that would address data needs in the MCH community at the same time as advancing the strategic goals of the MCHB Title V Program. The focus was on innovative approaches for improving data capacity in state MCH agencies and how best to address those two broad areas that were identified: the unevenness in capacity and the lack of standardization.

[slide 10] The process was to develop a wish list of objectives to address gaps and to prioritize objectives that were open to influence. So, we had a number of objectives that we considered, but there were things that we would not be able to do anything about, so we had to eliminate those. We came down to about 4 basic objectives. One was to develop a recommended standardized MCH dataset, and that's something we are going to delve more deeply in today.

But I just wanted—just for your information—I just wanted to also tell you a bit about the others. Secondly, there was an objective to promote the use and availability of real-time data. And in that regard, a workgroup is working on writing guidelines for real-time data use in conjunction with the NAPHSIS Provisional Statistics Workgroup.

We're also working on developing a strategy writing guidelines for data sharing and data linkage, compiling examples of successful data sharing and linkage, and writing guidelines for data sharing agreements. So, we have a workgroup that is working all of that. And, then finally, to promote the development and sharing of analytic tools we are building a repository of SAS or other program code to analyze data so we can share those tools across states.

[slide 11] So, getting back to the minimum core dataset—what does that entail? By our definition, it is a consensus-based, common set of MCH reporting measures with common definitions, data sources, data sources and data elements that would accommodate states at varying levels of data capacity.

The benefits of having such dataset are that it provides data comparability across states and regions. Also, in having a common set of data elements, it allows for sharing the analytic tools. States that are able to develop analytic programs—say in SAS, or SUDAAN, Stata or some other programming language—could then share these analytic tools with other states that did not have the resources or technicians to develop those programs.

Third, we would have greater consistency of data reporting over time and across programs. And finally, we have a means of very importantly supporting evidence-based policy and program development. By studying the programs and performances of their peers using comparable indicators, state policymakers may be able to better assess their own programs and performance. And this kind of consistency is vital to help inform policy in workforce planning as well as changes to meet population health needs.

[slide 12] The methodology that we planned was first to perform an environmental scan of MCH [maternal and child health] indicators. We included many Healthy People 2020 measures, all the old TVIS [Title V information System] measures, Medicaid child health measures, EDI [Early Development Instrument] measures—and it covered the gamut of health topics across infancy and childhood through adolescence, maternal care and postpartum care.

And the plan was for there to be first qualitative review of the measures. Members shared their knowledge of the advantages and disadvantages or the validity and non-validity of measures and also the ease or difficulty of finding data sources and the usefulness of data sources for each of the indicators.

It was also planned that we would have a formal evaluation. Members completed a formal evaluation of 114 indicators and that evaluation was planned or was modeled on the AMCHP Life Course Indicator Development process. The next step was to write an implementation guide and to pilot in states, and revise accordingly to feedback, and then finally to implement in states.

[slide 13] The workgroup had concerns. One was that they did not want to burden the states with additional reporting requirements. At that time Title V still had reporting requirements, and they just did not want to make extra work for states. In addition, they did not want to exacerbate the effective data capacity disparity by requiring low resource states to adopt indicators for which they would not have the resources to generate estimates.

The workgroup's solutions then, were that states would not be asked to report estimates to MCHB. They would simply be asked to report whether they had the capacity to report on certain indicators, and the methods that we developed for generating most of the estimates require a minimum of resources.

Finally the dataset was 2-tiered. So, there is a minimum set which all states are capable of generating estimates for and which they are expected to. Then there is a core set, a separate core set and some states will have to grow into the capacity for estimation with those. Some states—and there are states that will be able to do all of the estimates—probably.

[slide 14] To focus a little bit for a minute on the minimum data set, to talk a little bit about more of the features of that, none of the minimum indicators are new in a sense of they have all been reported before in the Title V system. All states can generate estimates for these indicators in a standardized way from a national data source. The guide for obtaining the estimates is written in a very user-friendly manner and it requires a minimum amount of staff time.

[slide 15] As far as the features of the core dataset, some of those are entirely new indicators that MCHB has never requested in the Title V system and in some cases, may not be currently available to all states if they don't have access to specific datasets such as Medicaid. There are also standardized procedures for obtaining these estimates, and sometimes they are from national data sources, but sometimes they are from state data sources, such as hospital discharge data.

There are also easy-to-follow directions, but they may require interagency data exchange or running a data analysis program using computer software. They may require more capacity than currently attainable by a state, but in those cases, be considered aspirational for a state.

The current status is the guide has been piloted in 2 states— Oregon and North Dakota—and we have spent a great deal of time revising the processes with the aim of reducing the complexity and improving the speed with which the task can be completed. The feedback that we've had so far is that the process of producing estimates has been informative, straightforward, and most of it can be completed in a day.

Some of the core measures that require obtaining data from other sources such as the Medicaid or datasets or newborn screening labs, may require more time, but most states already have these relationships in place, and the process of obtaining the data should not be terribly different than that in the past when states were reporting on the Title V performance measures.

[slide 16] I would like to address briefly the national performance and outcome measures in the context of the SSDI indicators. This slide is showing you the overlap of the SSDI measures with the national outcome measures on the left, and on the right, the national performance measures.

Work on the SSDI indicators began shortly before the work on the national performance and outcome measures and informed that process to that some extent. There were; however, different processes, and in the case of the national outcome and performance measures, those were developed by MCHB staff to fill the needs of the MCHB, the Maternal and Child Health Bureau.

On the other hand, the SSDI indicators were a consensus-based set of indicators developed by MCH peers and constituted what they felt should be reported or should be available to all states.

There is some overlap. We identified the national performance and outcome measures that were the same or very similar to the indicators—the SSDI indicators—and then harmonized the measures in terms of definitions and data sources so there would be no confusion about that. And for those that are the same, the states will have the pre-populated estimates that will be produced by a TVIS system, so they are all identified in the guide.

[slide 17] Also briefly, I would like to mention there are 2 major components of the guide. One is the PDF document that contains all the procedures for obtaining the minimum/core indicators, and that is pictured, a screenshot here [image shows on slide]. It may appear intimidating at first, but in fact, it is very user-friendly and Dina will show you more about that later.

[slide 18] Also, the second component is a workbook, and that contains worksheets for inputting primarily frequency data and a lookup table for using as a reference for the estimates. The worksheet and the workbook are synced to the PDF instructions so that as you progress through the implementation guide, you will also be progressing sequentially through the worksheets as well.

[slide 19] There are short term outcomes that MCHB has—or expectations that they have about how this will focus the emphasis for the SSDI funding and the types of data activities that states will engage in. For one thing, the Minimum/Core Dataset allows data analysis programs to be shared across states and regions to increase collaboration and data sharing, and it allows states to learn from each other. It also simplifies the task of responding to data requests coming from different governmental sources within and actually outside of states.

[slide 20] In the long term, the focus will be less on calculation of data and statistics for reporting to us and rather the emphasis will be on more on advanced analyses, digging deeper into the data. And along with that, we would like to see greater collaboration across states and regions about what works programmatically.

The corpus can be dynamic— the corpus of indicators. There are new indicators that can be incorporated using the same methodology. For example, adding the life course indicators, when that seems appropriate. And another focus will be on developing infrastructure, quality improvement and program effectiveness.

[slide 21] Future directions— there are some that are definite—some that are possible. First, we will complete the remaining objectives related to timeliness, data linkage and data analytics and make those

resources accessible for states. We will compile a Minimum/Core Dataset Implementation Guide for the territories, to the extent that that is possible.

And possible directions are that we can form regionally-based data workgroups to utilize the SSDI data tools to improve state-level analytics capacity. So what that means is bringing together all these tools that I have talked about and helping states to use them in meaningful ways. Another possibility is using Adobe Connect to stage state-level technical assistance workshops in things like data linkage and data analytics.

[slide 22] In summary, we got the the workgroup's message that SSDI funding is vital to states and it underpins their efforts to address issues of state-level data capacity, but that the data capacity across states is highly variable and MCH is in need of some level of standardization. And it is our hope that the MCH core data set will add a further support to state-level efforts to improve the quality of data collection, analysis, and dissemination.

[slide 23] I'd like to acknowledge the original SSDI workgroup you see here [names listed on slide]. This was the group of people that developed the objectives as a whole. As you can see [there are 5 groupings of names on the slide], there were state workers from a number of different states, there were CDC representatives, we had academics from around the country, our partner service organizations like AMCHP, NAHDO [National Association of Health Data Organizations] and NAPHSIS [National Association for Public Health Statistics and Information Systems] and MCHB staff from several different divisions.

[slide 24] But, I also would like to extend a very special thanks to 2 people: Dina Dickerson and Devaiah Muccatira. Dina being from, at the time, from Oregon in the Maternal and Child Health Section, and Dina has been involved in all aspects. She started with the original workgroup, she helped with developing the implementation guide, and she performed most of the pilot in Oregon. And Devaiah, he performed the pilot in North Dakota and provided us with very important feedback which we incorporated into the guide.

[slide 25] And with that, this is my contact information [slide shows her mail and email addresses].

Sarah Lifsey

Thank you so much. So, next I would like to turn it over to our next speaker, Ms. Dina Dickerson.

Minimum/Core Dataset Implementation

Dina Dickerson, MPH – Alumnus, State Systems Development Initiative, Oregon Health Authority, Division of Public Health, Maternal and Child Health Section

[slide 26] Hi. Thank you. Thank you, Mary Kay. So I am just going to get started here.

[slide 27] So first, I just wanted to say something real quick—how I was involved in this whole thing. I came into this world—I mean I have got 44 years informatics practice and scholarship experience—

8 years of that at the end of that, Oregon's Maternal and Child Health, and specifically working with SSDI.

In the course of working SSDI, that was sort of an informatics kernel for maternal child health in Oregon and the group that works with all of the programs. And what was obvious to me and to my colleagues who worked with me is that different programs were basically representing data elements in different ways and it was causing confusion, conflict and so forth and what was really needed is a standards-based minimum dataset that everybody would be reporting. If your program requires you to report breastfeeding at 6 months, that you are saying it the same way the next person in the cubicle 3 doors down is saying it.

So that's what we saw was needed. So I worked with the group, I helped develop the IG [implementation guide]. So when you go through the implementation guide, you will see stepwise instructions, images and links. Somebody had to do that [laughs], so be glad somebody sat down and did it, because it will make your life very simple to just go through this thing.

So then I also, myself and my colleagues—that you will see the list of in a minute—tested each one of those stepwise instructions, images, and links, and when we would find things that were not right, the wrong answer came up, or whatever, providing feedback so that revisions happened to the IG or to make them clearer or whatever. So we actually did that test.

And the other thing, provided perspective from the frontline of state data needs. I mean, basically, we're here trying to do this work, so we knew that a standardized minimum data set would simplify MCH indicator-reporting. The M/CDS [Minimum/Core Dataset] is the first step towards doing that, and I say "yay!"

The implementation guide makes setup really straightforward and can be done in a few hours. It seems lengthy—that is only because there are images to show you exactly what the screen looks like, and those are your templates. But it is actually very quick to go through, which you will see. And the M/CDS draws on prior MCH work—all of those links—CDC WONDER and all the other things that you will be hooking up to—that is all MCH work that is there for us to use. There are available tools and datasets, and they are sitting there ready for us to use and that is another "yay!"

[slide 28] So, the implementation itself really has 3 parts. The guide itself, and the guide contains the templates and the steps to obtain the indicator data, and the worksheet where your answers will be recorded, but the other piece of that is the Internet sites, such as CDC WONDER. We are going to walk through just a couple of examples, so you see what I am talking about.

But the key think about the IG—the implementation guide—it is accessible to any state, regardless of technical resources. All you need is the ability to open a Word document, and follow the instructions and an Excel document to record your answers, and then your indicators get calculated automatically. You also did not have—I do not have it here—but you also need Internet access to look up these sites. And again, it is the initial step—you know, cut us some slack—if you find an error, report it to us, we will fix it as we receive feedback and learn how to best support the state programs.

[slide 29] So, here is what the worksheet looks like; it is an Excel spreadsheet [slide shows image of a worksheet]. Each one of these tabs—so we are looking at worksheet 1—it is the introduction. And then you have population and the live births and birth indicators and mortality and so forth; every one of these tabs has the content that you need to report for that thing. And you will see as we go through these things that it turns out not to be that odious, and also links to data sources for one of 13 indicator categories. On the very last tab of this spreadsheet are your summary tables for the minimum and core. They are automatically calculated.

[slide 30] So, now let us go to tab 2, population for 2013—and you need your population data because this becomes your denominator that is used in the calculations on subsequent pages. So the first thing you do—and you notice everything you are looking at is literally listed out of the implementation guide and sort of scrunched down here [slide shows images of the browser screen and details of application and the spreadsheet] to just show you these things are not horrible. And I put, where I could, what it took me to do it. Even if you double the amount of time, we are not talking about giving your life to the cause here. So to create the population tables took about 15 minutes altogether.

So here first, go to the CDC WONDER site, select the bridged-race population. It keeps putting up the next choices, so then select the 1990 through 2013 data request. Then organize how your table is going to come out, and in this case, it is state and years—yearly July 1 estimates and age. So each one of these things in the implementation guide shows you the template and what your answers should be for that thing.

Then select your state from location options. I did not include that, because I figured everybody would know their state, and I did not have to show that one. And then set age, race, ethnicity, and yearly estimates, and gender as shown, which is basically "all." We are getting all sexes here from ages 0 to 19. Then hit "send request," and it comes back with the report. The table has population values for the 0 to 19 age group.

[slide 31] You basically take those numbers and record them here in this column [slide shows details of spreadsheet], your both sexes 0 to 19. Then you go back to that same screen, where I am saying return to request form, starting up on step 6, so now we just want females; you set females for the gender menu, and rerun it, so you get those numbers and record them there. Then you go back to that same page, and pick females 20 to 24, rerun it again, get those numbers.

The summary totals over here are going to calculate automatically once you have these things in. And again, these are the things that are going to end up being your denominators in subsequent worksheets, so it is kind of nice to have it in.

But anyway, that whole thing, when I sat down and did it myself, and again, even if you took twice as long, it would not take you that long. It took me about 15 minutes from the time I started until the time I had the thing filled out. So, it's not terrible.

[slide 32] So then the next worksheet, the live births; we just keep drilling down. So we go to the same site again, this time picking births from the WONDER database [slide shows images of on-screen

database details]. Select natality for 2007 and 2013. And I just want to reiterate here— I am literally—I have picked these images up from the actual implementation guide and I have put them here and scrunched them onto this page just to show you it is not a lot of work; to get the live birth data took 7 minutes.

So, organize the table layouts this way. Again, select your state, set all for "all" the maternal characteristics, all except year 2013, for birth characteristics. Set maternal risk factors to "all;" set your other options to this, and click send. Get your answers, and record the total live births on worksheet 3.

[slide 33] Which turns out to be that number right there [slide shows details of database screens and spreadsheet cells], total live births—we will look at the whole screen in just a minute. But then drilling down further, you just keep returning the request form tab to get further drill-down on these things.

So now I want it by birth weight, so I select it; here is what I pick for less than 1500, and I run it, and I get those numbers that get recorded right there. Then I go back, I change it to less, or I add up to 2500, I run it for 2500; I put that…less than 2500, I put that one there. Then I do over 2500; I write that number there. So I have just filled in all my birth weights.

Then I go back. I add age of the mother on to my organized table layout. I pick 15 to 19 years, and I get my teen birthrate number, and so forth. And then I ran it for black and white by going back, changing my organized table to Hispanic origin, and selecting non-Hispanic white and black for Hispanic origin and getting my numbers that are then ready to be recorded on the worksheet.

[slide 34] And here is the entire worksheet with all those answers [slide shows details of spreadsheet]. So again, it is not hard. It is not complicated.

[slide 35] You get a free ride for worksheet for the birth indicators get auto-populated once you enter the data from the other things, so that took 0 minutes [slide shows spreadsheet image].

[slide 36] So moving into something a little bit more involved—you notice this one took 17 minutes —I am sorry; it is a busy screen [slide shows details from database screen details]. But just to record what you need to do for the mortality indicators, select linked to birth and death, and then everything is the same until you get down to infant death. Select cause of death, and you pick "all," and set it for ICD-10 codes, and all ages and genders and so forth, and generate it. Again, click "send," generate the report, the report comes up with your answer. There is the answer. You take that number, and you record it in that cell.

[slide 37] So, and then here it is for black and white [slide shows image of screen details for database and spreadsheet]. You would leave things as they are except change Hispanic origin to black and white, and then rerun it, get those answers. Just one note here—if you have suppressed values such as that which you see right here—CDC WONDER will suppress the values under certain conditions, and the table provides the option to do 3-year estimates. So you do have that option as well, which I am not actually showing here.

[slide 38] Anyway, all of those things get entered into the mortality indicator worksheet. And just so you know, you only need to worry about the red cells, because the yellow cells are only used when the 3-year estimates are used because 1-year values are suppressed. So ordinarily you are going to be filling in the red here, otherwise you will fill in the yellow for that thing [image of spreadsheets shows that some cells have backgrounds of differing colors].

[slide 39] So that is all I am going to show in terms of the actual "what it looks like to go through the implementation guide." I'll just show you now what the other worksheets are. You have got perinatal indicators [slide shows spreadsheet screen image]. Again, this was not a major investment of time, and these are core indicators, so you may not even have all of these things—so pregnancy weight gain or something—you may not have everything, but basically again, perinatal indicators was quick.

[slide 40] Newborn screening indicators—2 minutes for hearing loss—and other indicators may take longer just because you have to go to somebody else for the newborn screening [slide shows spreadsheet screen image].

[slide 41] Then infant care—2 minutes—except back sleep position which requires PRAMS data. So we tried to give you estimates where we could [slide shows spreadsheet screen image].

[slide 42] Here we have nonfatal injury, and this one is a core, and the time varies, because it is again access to hospital discharge data, and so different states have different access, and so you know—who knows?—hopefully not very long [slide shows spreadsheet screen image].

[slide 43] Risk behavior indicator—3 minutes—that should not be hard [slide shows spreadsheet screen image].

[slide 44] CSHCN indicator [slide shows spreadsheet screen image].

[slide 45] And then services indicator—10 minutes—but then other things may take longer, because you have to get the core data—Medicaid data—so that may take longer, or you may not even have it [slide shows spreadsheet screen image].

[slide 46] And then demographic indicators—5 minutes—these are readily available [slide shows spreadsheet screen image].

[slide 47] And data access indicators; and again, the implementation guide has every single instruction, okay? Just like I was showing you those images, you are going to have the same thing for every one of these. You can start and stop as you see fit [slide shows spreadsheet screen image].

[slide 48] So then, after you have gone through that whole thing, you are going to end up with your lookup tables. So these tables—your minimum dataset and your core dataset will automatically calculate. They are the last tab in that spreadsheet, and they become the thing that is sort of your go-to information [slide shows spreadsheet screen image].

You do not need to go all the way back through calculating anything, because you have already got it nice and handy here, and this becomes what actually use—the result column is what actually gets used

[slide 49] And here it is for the core. Some core values show up as 0, because states will not have access to the data, so we will not have entered base value for the worksheet, so it cannot calculate anything. The lookup tables are intended to be your go-to reference without needing to search the source, how we—you know—what we went through earlier to create it [slide shows spreadsheet screen image].

[slide 50] Acknowledgments—these are people at the Oregon Health Authority plus my husband and son [laughs], who all contributed to this and just wanted to put their names up there, so let us give them a shout-out, because they helped.

[slide 51] And then this is how to contact me, and that is it [slide shows Dina's email address and phone number].

Questions and Answers

Sarah Lifsey
[slide 52] All right, great, and thank you so much. And thanks again to both of our speakers today. It has been a pretty engaging program, and we already have some questions coming in. [slide 53] And my first question is from Sarah, and it's for Mary Kay.

Do all 50 states have the SSDI grant?

(Mary Kay Kenney) Yes. I actually am not the project officer for the SSDI funding. My office, which is the Office of Epidemiology and Research, basically acts in part as technical assistance, but that is my understanding that all 50 states have the SSDI Grant, and they apply for it, and it's a 3-year cycle.

Sarah Lifsey

[slide 54] Great. I have a similar question from a couple of different folks which is:

How and when can we get a copy of the implementation guide, or how can we access the implementation guide?

(Mary Kay Kenney) After the AMCHP conference, we will be posting the implementation guide. The actual project officer is Scott Snyder in the Division of State and Community Health, so he is the project officer, and for the most part, the person to contact for the questions regarding the grant. I can act as, like I said, as a technical assistant, but they will decide how to send that out, and probably Scott will be sending that out in a Listserv to the SSDI coordinators.

Sarah Lifsey

[slide 55] Great. The next question I have is from Don:

Can you clarify if this new tool is something that we need to print and submit to HRSA, or is this something that is intended for local use?

(Mary Kay Kenney) Well that was one of the tenants was that states do not have to report this to us. We will update this yearly as a tool for the states and send it out to the states, but they are not expected to send anything back to us.

Sarah Lifsey

[slide 56] Okay.

When you say you are going to update yearly, do you mean the implementation guide and the worksheets that go along with it?

(Mary Kay Kenney) Right, right.

Sarah Lifsey

[slide 57] Okay. The next question I have is from Sarah who wants to know:

When will that session at the AMCHP conference on this topic be held?

(Mary Kay Kenney) I believe it is going to be on the 25th, I am sorry, I cannot remember exactly, but please, I can get you that information if you contact me via an email.

Sarah Lifsey

[slide 58] Good. The next question I have is—I think—for Dina:

If we find an error in the guides or the worksheets, how do we report it?

(Dina Dickerson) Mary Kay, should that come through to you? How do you want to handle this because we have not—in an official way, should it be coming to you?

(Mary Kay Kenney) Yeah, just contact me with any technical questions that you have regarding the implementation guide, its use, or function.

Sarah Lifsey

[slide 59] Okay, great. The next question I have is from Kathy, and it is:

If we do not submit the data to MCHB or to HRSA, how will we be able to see other state's data or communicate about trends with other states and within states?

(Mary Kay Kenney) Well, as I kind of alluded to, the expectations then are for states to work together, so you do not have to come back to MCHB to access another state's data, but you have direct access to a state, and you would be better, in terms of thinking about developing relationships with maybe states in

your region, or forming regional workgroups to delve into whether states have similar problems—states in your area or just maybe the state next door—and that is part of what we want to see is states looking to each other and forming relationships and using this data to develop priorities for their interventions.

Sarah Lifsey

[slide 60] Okay. This is a question for both of the speakers:

Do you have any advice for developing kind of data sharing agreements with other states or jurisdictions along those lines—any models or best practices?

(Mary Kay Kenney) Well, we actually have put together a kind of a template. It is kind of a modular form where you can pick and choose parts to put into, as needed, to put into a data agreement, so we have the template as a whole, but we have to submit that to a workgroup feedback process. So that should be out pretty soon.

(Sarah Lifsey) Okay. Will it be disseminated in the same way as implementation guide and worksheets?

(Mary Kay Kenney) Yes.

Sarah Lifsey

[slide 61] Okay, great. I have a question from Kathy:

If these data are essentially for local use, but we have more current state data on one or more indicators, wouldn't I be able to use that more current data instead?

(Mary Kay Kenney) Well, the yeah, the state or the implementation guide targets a year—it targets the most current data, and it targets data from a national data source. So that is part of the standardization process that it comes from. You may have your own state data, but these indicators are based on national data sources when they are available. So it is pretty much available for all states at the same time.

(Sarah Lifsey) Okay, great.

(Mary Kay Kenney) And I should say, I should speak to—if you have provisional data, say for infant mortality and you want to use that, then that is a given that you can go ahead and use that. But coming from a national data source then allows us to compare indicators across states so that you can—it is good for then looking at trends. But if you are say, developing strategies for infant mortality in the short term, you may be having to use provisional data.

Sarah Lifsey

[slide 62] Okay, great. I have a follow-up question about data sharing from Tanya:

When you say data sharing agreement, are you speaking about aggregated data or record-level data that is shared between states?

(Mary Kay Kenney) Well as far as the one… the template for data sharing agreement that we put together, it basically can be used for whatever your data agreement needs are.

(Dina Dickerson) I think it was intended to be used for record level.

(Sarah Lifsey) Okay, but the template could be used to for other kinds of data?

(Mary Kay Kenney) Yeah.

(Dina Dickerson) Yeah. The record level is obviously more intense, but yeah.

Sarah Lifsey

[slide 63] I have a question from Margaret which is:

Would it be possible to share a list of the contact information for all of the SSDI project directors in each state, so that folks in the states know who to contact for collaboration?

(Mary Kay Kenney) That is a question I think you would have to direct to Scott Snyder in the Division of State and Community Health, because he is the Project Officer. I'm not sure about that, I personally do not see a problem with it, but that is a question you would have to direct the question to him, so mssnyder@hrsa.gov.

Sarah Lifsey

[slide 64] Okay, great. I have a question for Dina:

You shared the time estimates that you had for each of the individual sections of the worksheet, but about how long did it take you overall to complete the worksheet would you say?

(Dina Dickerson) It was a few hours, and it elapsed over a day-and-a-half, just because I had other things on the plate, and then I would stop on it and come back, and so forth. If I added it all up, it would have been 4 or 5 hours, I would guess. But in a day and half's time, I had the whole thing done.

(Mary Kay Kenney) I would add to that, as I indicated there are some that require outside contacts—you know—and exchange of data, so for what Dina is talking about is those that do not require that because that will be variable.

(Dina Dickerson) Yes, exactly. The minimum is what I am talking about. The minimum data set took a few hours.

(Mary Kay Kenney) Right and a some of the core do not take that much either, that they are in the core set because they were entirely new to the states— you know—they were not TVIS measures, and so they were put in core for that reason, but they do not take that much time either.

Sarah Lifsey

[slide 65] Okay, great. The next question I have is for either speaker:

Is there a timeline—an expected timeline—for states to grow into the minimum set and into the core set?

(Mary Kay Kenney) Well that, too, would probably be something to direct to Scott. We will be working on moving states forward to be able to do these things, but if a state just can't—the idea is to move states forward and to try to diminish that gap between states with high capacity and states with lower capacity. So, we'll be maybe even calling on states with higher capacity to work with us and with states with a lesser capacity to try to share resources in terms of data to bridge that gap.

(Sarah Lifsey) So almost a peer-learning model?

(Mary Kay Kenney) Yeah, if… yeah.

Sarah Lifsey

[slide 66] Okay, great. I think we have time for one more question, and the question is for either speaker or both speakers:

Have there been any thoughts about this kind of data standardization outside of MCHB and HRSA, so just with other branches, other groups?

(Dina Dickerson) The answer is yes. I mean there is quite a bit of work going on. So especially with all the health information exchange stuff, I was part of the Public Health Reporting Initiative, and we looked at, I mean, basically, we collected user stories and did the analysis for 5 different areas—maternal child health being one of them—and especially newborn hearing screening became a test case for that. But also communicable disease, chronic disease; there were 5 of them—I am drawing a blank—sort of infrastructure stuff.

Anyway, basically we developed in the course of that work, the public health Data Harmonization Profile. It is available online at the Public Health Reporting Initiative site. Basically there are national movements about trying to bring all this altogether, because there are so many silos in public health and it is so hard to put the data together, people spend all their time trying to put data together rather than the data is already the same, we just need to do the analysis and have it feed into policy and support evidence-based practice and all of that.

Adjourn

Sarah Lifsey

[slide 67] All right, great. Well, I think that is all the time we have for discussion today. Answers to any questions that we did not get to during our Q&A period today will be posted in writing along with the program archive [there were no extra questions], and that archive will be available on the DataSpeak website. You can access it at your convenience. If you think of any other questions, you can submit them to us via email through the next week using the email address on the screen, dataspeak@altarum.org.

[slide 68] Before you go, we would like you to know we will be broadcasting more DataSpeak programs in the coming months, and announcements about these future programs will be sent our via email to everyone who registered for today's program, as well as on the DataSpeak website.

And the last thing, before you go, is we would really appreciate it if you take a moment to provide us with some feedback on today's program. It is really important to us that we have your input on this session and your recommendations for future programs and topics. It is a very short survey, and if you click on the evaluation link that is on the screen now, the survey will pop open in a new window.

And lastly, I would like to thank all of our speakers for making this such a great program. Today's program is now complete. Thank you for everyone 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.

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