Centers for Disease Control and Prevention

EARLY HEARING DETECTION AND INTERVENTION
Special Topics Teleconference

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Roughly Edited Transcript

Overview of the New CDC-EHDI Data Survey

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>>**John Eichwald (CDC)**: Good afternoon. This is john Eichwald from the CDC-EHDI program. I would like to welcome you to our EHDI special topics teleconference. This afternoon we have a great call planned. It's related to the new CDC-EHDI screening and follow up survey. Hopefully you've received a copy of today's PowerPoint presentations that was e-mailed out last Friday.

Today's call is about the new CDC EHDI screening follow up survey. Developed the survey to provide accurate and detailed data for the "1-3-6" national goals, and we've really developed this in a manner that we hope will collect consistent data across all jurisdictions. This is really been complicated by the fact that screening procedures vary among the various jurisdictions and even vary at the hospital level and the reporting and diagnostic and intervention data also varies greatly.

We have gone through significant efforts to reduce the burden for reporting the one, three, six data to the CDC. We understand that because the data is going to be reported to us in a different manner, it's likely that the reporting of the data towards the national goals may change from previous years. However, we are prepared for that. On the other hand, we really feel that this survey levels the playing fields for all the EHDI programs and it will be able to provide more accurate data to determine the progress related to the national goals and for the healthy people 2010 objections. Many hundreds of hours have been involved in the development and approval of this survey. I would like to thank all those who have participated in the development. In particular, I want to thank Marcus Gaffney, Craig Mason and Pam Costa, members of the DSHPSHWA, and to those within state and territorial EHDI programs who have provided their input.

>>**Marcus Gaffney (CDC):** Thank you, I appreciate that. I'm with the CDC EHDI program here in Atlanta. As john said, this is very different than past collection efforts. The goal is to gather more consistent and complete information. Previously available EHDI data were often inconsistent, which made it hard to generate accurate estimates of national screening and follow-up rates and answer questions from about progress from various stakeholders.

This is why a new survey has been developed. While it may be challenging to complete, we are going to do everything we can to try and make the process as easy as possible.

My talk today will closely follow the PowerPoint presentation that was sent out before this call. As stated, the goal of this voluntary response survey is to provide more accurate data. The data gathered from the survey will be used by both CDC and HRSA.

There are several uses for this survey, including providing data to states, the general public, and other interested persons. We also think it will help determine progress related to the national EHDI goals as well as providing data for healthy people 2010, which is why demographics information is requested.

Regarding background, the survey was developed in collaboration with the members of DSHPSHWA, and several other partners. This included feedback from several states, which was immensely helpful in identifying things that needed to be addressed. Thank you to all of you for that.

The survey compliments the items recommended by the CDC-EHDI data committee. The survey was also approved by the federal office of management and budget (OMB) in October 2006.

Moving on to slide four now, this survey is going to replace the survey that was sent out previously by DSHPSHWA. It's a decision we made in conjunction with them. As a result you will **not** be receiving two separate EHDI surveys. Another key point is that all data reported should be based on **occurrent births only**. You will see this reminder in several places in the survey.

When the survey request is sent out, which we are hoping will be t by the end of January 2007, there will be an explanations document sent along with the request. The explanations document will provide an explanation for each data item in the survey and follows along with the exact order of the online survey. If you have any questions about the survey, please feel free to contact me. My name, phone number and e-mail address will be listed on most pages within the survey.

Moving on, I now want to give you an overview of the design of the survey. I am going to be talking about some of the features of the survey then I will show you specific screen shots and going over different scenarios from the survey itself.

You may know at this point, the survey is going to be web-based, so when the request is sent to respond to the survey, there will be a link within the e-mail request. The survey requests **aggregate data only**.

The survey has been designed around three key parts. Part one concerns screening. That's hearing screening, diagnostics and intervention. Part two is concerned with a type and severity of hearing loss, and part three relates to demographics. That's related to information requested healthy people 2010. You will be able to include general comments.

Moving onto slide six, I want to go over a couple of features. One of the things we built into the survey is that it's designed to calculate the totals for certain items or certain fields within the survey. All of the total fields in the survey are highlighted in <mark>yellow</mark>. If you are looking at slide six, you should see where it says "total pass." I plugged in numbers there, so you can see that all
Those "total pass by one month of age, etc will be added up by the survey and they'll give you a total of 250. That is what we mean by automatically calculated.

To calculate these totals there is a button at the top of each page of the online survey. This is shown on slide seven that says calculate totals. It is going to be at the top of the survey in the middle and that's what you have to click to get the survey to sum up the totals. You can proceed with the survey without hitting that totals button though. That button there is to help you see what the total comes out to make sure it looks right to you. Make sure that number looks correct. Again more test data plugged in there to see how the total comes out there.

In addition, the survey has the capability to generate error messages if totals don't match. The purpose of having the error messages is to make sure that all the births (*or other values, depending on what part of the survey you are working on)* are accounted for. Essentially, it is to make sure that all the infants and children are accounted for in the survey.

For example, if you have 1,000 births reported, all the births have to be accounted for in that section. Shown on slide nine is an example of the error message that the survey will give you if this happens. It will tell you what values don't match. It will ask you to please "click here" and go back and check the data

and correct it any errors, which means go through the data and see if you can identify the fields that maybe incorrect and please enter in the correct number(s).

As a basic example, assume you enter 1,000 births and you say that the "total screened" plus the total "not screened" i equals 750. In this example there is data missing for 250 children (1,000 – 750 = 250). If you try to continue with the survey, with data missing for those 250 children you will get that same error message that's on slide nine. You will then need to go back and fix it.
Please note with that error message that you cannot continue with the rest of survey until you correct the error(s). So, for example, if you get this error in the screening section, you won't be able to continue to the diagnostic section until you correct that error by accounting for those missing 250 children. This function is built into the survey to try and ensure a higher quality of data by minimizing oversights, etc.

>> Luella: This is *Luella* from Hawaii. I have a question. Suppose you have a hospital that does not report child specific data or doesn't report their data and you have those 250 kids. Where do you put them?

>>Marcus: there is a category for missed under the hearing screening section where they can be reported.

>>Luella: This hospital says they do screen them. They just don't tell us and we don't have the child specific data.

>>Marcus: Do you have the aggregate data from that hospital?

>>Luella: Some of it, but it's not going to be in this format.

>>Halle: This is Halle from California. We're going to have a similar situation as I mentioned to you before the call. Babies who get transferred, we don't get infant   specific information on all babies, so we're stuck with aggregate information and some babies may be counted more than once or some babies may not be counted at all.

>>Marcus: If the hospital is just telling you, we screen the kids, but you don't know who they have screened, the ones you can't account for should be reported in the "missed" category. If you do know the hospital screened those 250 kids, and those 250 passed the screening, you should be able to report that in the appropriate total passed field, or if they didn't pass the screen, you put them in the total not passed field. The idea is to make sure that all the births are accounted for.

>>Unknown: It's going to be easier to deal with in this section than it is on part three, because then we're going to be stuck with more current births than we have the ability to breakdown, according to the other stuff.

>>Marcus: Now, part three demographics doesn't have any error checking built into it, which I'll talk about in a little bit. We thought that might cause a problem. So it's really only part one of the survey that has these error checks built into it. Type and severity doesn't and demographics doesn't.

>>Minnesota: Just a quick verification. If we heard this correctly. Is the missed category also for the unknowns?

We don't have mandated reporting in Minnesota, so there's several thousand we know nothing about, so well can put them there.

>>Marcus: Yes, that's where they should be reported. The missed field includes those where screening status is unknown.

>>Halle: This is Halle in California again. We actually have a category of not medically indicated, so that would be for babies who are too sick to be screened. So I don't know if your explanation document will

address that. I'm not exactly sure where those these kids, it's hard to know. Some of them we know about, and some them we don't.

>>John: We're trying to capture the most accurate data we can in terms of the screenings that has occurred and the outcomes of those screenings, if that helps.

>>Luella: This is Luella in Hawaii again. It sounds like missed is going to be anything other than pass or refer.

>>Marcus: the actual explanation under missed from the explanations document is "the total number of infants that did not receive a completed hearing screening regardless of the reason, just excluding the children that died or the cases where the parents declined the screen." That's the explanation for the missed category. It also points out that this also includes infants who were only screened in one ear (i.e., where both ears were not screened at the same time).

>>Unknown: They are considered a miss if they were only screened in one ear?

>>Marcus: Yes, if there's no documentation of both ears being screened at the same time during the future visit.

>>Minnesota: How is that different than not screened?

>>Marcus: There is no separate "not screened" category on this survey that you can enter data in to (*there is only a yellow field where the total will be automatically calculated*). The two bullets I just mentioned are listed under the same "missed" category. There is no separate missed and not missed category. They are one and the same.

Talking about actually completing the on line survey, I want to point out slide 11. The draft of this survey that is available online (www.cdc.gov/ncbddd/ehdi/dips.htm#survey) says "draft", but all the data items are finalized. That will show you the data items being requested on this survey.

Moving onto slide 12. When you receive the request to complete the survey, and you click on the link, this is the first screen you're going to see. This is a screen shot of it. This covers parts one and two of the survey. So part one includes screening diagnostics and intervention and part two includes type and severity. Demographics is included in the separate part 3.

On the first screen of the survey there will be required language about the public recording burden statement that is required by OMB. What is not shown on this screen shot is if you scrolled down, basic information about the survey and brief instructions are also included. You should be able to see the blue button near the top that says "begin survey parts one and two." Please press that button to start the survey.

I want to point out a couple things (slide 13). In order to go to different sections within the survey you will use what we will call a menu or a navigation bar near the top of the screen. It will say "hearing screening," "diagnostics," "intervention," "types severity," "review data," and "finalize." These represent different sections or pages and are underlined and in blue. You can think of these as links that are similar to what you would find on a website. To go to a different section you simply click on the link you want (e.g., diagnostics).

Whatever section/page you are looking at will be highlighted in yellow in this menu bar. On this slide, you should see that "hearing screening" is highlighted in yellow. This is how you know where you are in the survey.

When you are done with the hearing screening section and you want to continue with the survey, you simply scroll up the page and click on the "diagnostics" link and so forth.

Moving on, the first section you come to in the survey is hearing screening, which will be highlighted in yellow in the menu bar at the top. You should also see near the top, in the middle, is the "calculate totals button". That's how you get the numbers to appear in those yellow fields..

Please note you **cannot** type numbers into the yellow fields. You can only put numbers in the gray fields.

I'm on slide 15. I want to now go over a couple of data definitions that relate to the screening section. Data is being requested for the final hearing screening
In this section.

>>Unknown: What do you mean by final?

>>Marcus: If an infant was screened before hospital discharge, but you also have a record of that same child again being screened at two weeks, please report the hearing screening results for the screen that was done at two weeks, not the one before hospital discharge, but for the one that was done at two weeks. This is in those cases where you have multiple screening records for the same children. We want to capture that final screening data.

Another note is for the purposes of this survey is that a <u>month</u> is always going to be defined as 30 days. So one month is 30 days, three months, 90 days and so on. That's going to be standard throughout the whole survey. This will be denoted in the explanations document that you will receive.

Slide 16. I wanted to point out something else. At the top, the very beginning of the screening section, you're going to be confronted with two fields to start with.

The first one is going to say total "occurrent births" in black italics. That's where you put in the total occurrent births for your state or territory. That number may come out of your EHDI database or wherever you usually get a birth number.

There's also a field under that which is circled in red on this slide. That "total occurrent births reported by vital records" field is meant to be the actual number that comes from your state vital records program, if applicable.

This field is more of a quality assurance indicator. It doesn't affect any of the automatically calculated figures in the survey. It's just to see are there large differences between those numbers, between what is in the EHDI database and what is coming out of vital records. It does not impact any of the totals throughout the survey and it doesn't show up anywhere else later in the survey.

>>Halle: This is Halle from California. So does that mean when I put in total occurrent births, you're only interested in the births that we had reported to us, which is only in -- that's about 75% of the births in California.

>>Marcus: It should be all the births you have. It's whatever number you normally report in your database. If there's a separate number you can get from vital records, that's where that will be reported.

The survey is supposed to cover all occurrent births in your state, not just that 75% number. If you can get data from your separate vital records department, if data came from there, that's where you plug in that circled data.

>>Halle: I was assuming that I would report the vital records under total occurrent births, and then the ones that don't report to us would all go in missed.

>>John: That's the right thing to do, Halle.

>>Marcus: Ideally these two numbers should be the same, or very close.

>>Washington: We do not have the military hospitals reporting to us. There are three military hospitals in our state so our vital records are going to be about 1500 births higher than the births records that we would normally calculate so I'm wondering if you have a place to explain in the survey why there's a difference between vital records.

>>Marcus: The best place would be the general comments field which will be the end of the survey. We'll be going over that field later on in the presentation.

I'm moving onto slide 17 now. These are just different scenarios to show you how to report.

Scenario one is saying if an infant did not pass any hearing screening before they're discharged from the hospital, but they pass a follow up screen that was performed at 21 days post birth, you would report those under the pass before one month of age, because the follow up screening was done before the infant was one month of age.

Scenario two, the infant doesn't pass a hearing screening before discharge from the hospital, but they do pass a follow up screen that was performed at 45 days post birth. In that case, you report them in the screening category that's called pass after one month but before three months of age.

Scenario three. This is if an infant does not pass a hearing screening before discharge, does not pass a follow up performed, and is referred to audiology. You just report them in the not passed before one month of age.

Scenario four is just talking about the infant not passing and being discharged from the hospital with no follow up being documented. So you only have the record of them not passing the screening, being discharged, and that would be under not passed before one month of age.

Scenario five (on slide 21). It's just saying infant does not pass any screening administered before being discharged, did not pass follow up screen formed at 45 days and is referred to audiology. You also put them in the not passed after one month, but before three months, so those are just different scenarios. Hose scenarios will be included in the explanation document too.

I'm on slide 22 now, which is the diagnostic section. Once you finish the hearing screening section just scroll back to the top where there will be that menu bar. Just click the diagnostics link and you'll be taken to the diagnostics section/page.

The first thing I want to point out, if you look under the item at the top that says total not passed, parentheses hearing screening, the yellow field, whatever that number was in the hearing screening section, say 1,000, that same 1,000 will automatically be populated in this field. That's what all the error checks are going to be based on for the diagnostic section.

All the kids that are in that not passed field have to be accounted for somewhere in the diagnostic field, whether they have normal hearing, a hearing loss or no diagnosis or undetermined. All need to be accounted for somewhere on this diagnostics page.

Moving to slide 23, these are just definitions. If there are records of more than one evaluation available for a child, we're requesting that data be reported only from the initial comprehensive audiological evaluation. That's the first comprehensive evaluation if there's more than one on file. Again a month is equal to 30 days.
>>Luella: This is Luella from Hawaii. What do you mean by comprehensive evaluation? What are you including in that?

>>John: I pulled that term from the national goals. It really is going to be up to the EHDI program to determine what constitutes the first comprehensive evaluation. The reason we're rally going with that first diagnosis is we're fully cognizant of the fact that some children go through a diagnostic odyssey of being seen for several evaluations and might be several diagnoses. We want to capture that first real diagnosis.

I use the term comprehensive only because it was listed in the national goals. That's really up to the program to make that decision of what's that true initial diagnosis.

>>Unknown: Are you talking about the first ABR?

>>John: Some of the scenarios may show some of this, but again, I mean it's almost in a sense best judgment of what's really the true diagnosis.

>>Mary Catherine: This is Mary Catherine in Rhode Island. Just talking about that, I think the spirit of it is that you want to know the child is being seen by three months of age. As long as there's some sort of hearing loss diagnosis, even if it's still undetermined within the three months, that should still count, as long as the child is still being seen. Would that be an appropriate way to categorize that child?

>>John: I wouldn't say undetermined. We really do want to have that -- an audiologist say what the diagnosis for this child is.

>>Mary Catherine: But they are saying the diagnosis for this child is undetermined at this time, but they're still being seen for follow up. But they may be seen by, you know, two months and two weeks of age, but they don't get the firm diagnosis of profound sensorineural until they're four months two weeks old.

>>John: The goal is to have that diagnosis done by three months. What we really want is when was that first diagnosis made and that's why we're pushing for that first diagnosis.

>>Halle: In California, we use type and degree of hearing loss as our identification of hearing loss.

>>Mary Catherine: That's what we use as well here in Rhode Island. I'm saying that for some kids who may take three trips to the audiologist to get a firm, they may be in process, which is how we would interpret it as they're being seen, they're getting services, but they just don't have a clear diagnosis.

>>John: We have that in process category to be reported. We can come back to this.

>>Kathy: This is Kathy in New Jersey. Because the denominator here is kids that weren't passed, and I'm presuming that any child that has a late onset hearing loss should be left out of this entirely. So they passed their screening at birth, but at whatever, six months of age are diagnosed with a hearing loss, they're not to be included?

>>John: The answer is yes. Please stay tuned.

>>Stacy: This is Vermont. Where do we capture families that might decline in patient services, or the initial screening, but end up pursuing testing later, they go home and decide they want to have it done.

>>Marcus: I think we're also going to hit on that in- just a couple of minutes when we talk about late onset. If that doesn't answer your question, let me know after we get to that section, if that's okay.

On slide 24, scenario six, say you have an infant that's first seen by an audiologist at 45 days, and then eave an actual diagnose sick ABR done at 60 days which indicates a permanent hearing loss. That child should be reported in hearing loss identified before three months of age. That's the appropriate category. Regarding scenario seven, we take a slightly different situation where the infant is first seen by the audiologist at 45 days, but not receiving the diagnostic ABR that indicates permanent hearing loss until they're 150 days or five months of age. In the case like that, you report them in hearing loss identified after three months, but before six months of age.

One more scenario: if an infant seen by an audiologist at 45 days and then has an audiological assessment at 240 days or eight months that indicates permanent hearing loss, you report that child has a hearing loss identified after six months of age.

Now, regarding late onset cases, when you're on the diagnostics page. I'm on slide 27 now by the way. When you're on the diagnostics page, as you scroll down the screen, you'll get to -- you see at the ends of first page, the last section first table says no diagnostic determined. You'll seat note that says attention with a couple of bullets there and another table, that's what has a red circle around (on the slide) that says "permanent hearing loss not included in total not passed."

That total not passed is just talking about the number that came from the hearing screening section that was automatically put at the top of the diagnostics page. It's one of those auto yellow populated fields.

This is the section where you can report those kids that, say, passed their initial hearing screening but were later found to have a hearing loss, a late onset hearing loss. The are reported on the separate table on the diagnostics page.

I want to point out on here that when you're reporting information for early intervention, which is the next section, these late onset kids should **not** be included in the totals for intervention. The logic behind that is because the survey is designed to collect 1-3-6 specific EHDI data for those children that didn't pass the hearing screening, went to diagnostics and then went to intervention.

There's quite a few notes on this page asking just to report intervention data for those kids reported above, none of the late onset.

>>Luella: I have two questions. Where do we put children where we've been informed that they have a hearing loss, but we don't have a date of diagnosis?

>>Marcus: Hearing loss, age unknown. If you look at slide 27, the last row there on the table says hearing loss identified, age unknown.

>>John: please note that you are not seeing all the fields on these PowerPoint slides.

>>Marcus: These are just screen shots. There's an actual field for total normal hearing and total hearing loss, and there are both fields for hearing loss, age unknown.

Moving to slide 29, when you are done with the diagnostic section, scroll up, click on the intervention link. S you'll see on slide 29, intervention is highlighted in yellow in the menu bar. This is just a screen shot showing you part of the intervention page.

The first number you'll see there in bold italics, first category, says "total cases hearing loss". That's going to be taken from whatever number was in the diagnostic section. So if that was 100 children with hearing loss, that same 100 number will be shown here in the intervention section. There will be error logic built in here. This means that is if you look at just that first category that says referrals to part c, the total of those fields, of those four rows there have to sum up to that same 100. When it is asking about the number of kids that are enrolled in part c and non-part c services, there's no error checking built into these sections.

Now I want to move onto part two of the survey now. As noted part one and part two are combined.

After intervention, click on the "type severity" link. Slide 30 shows a screen shot. There are two more tables not shown on this slide. Part two is asking for type and severity of identified hearing loss **by ear**. It's not asking by child.
The categories here are going to be pretty much the same as what was on the previous DSHPSHWA form as far as asking for sensorineural loss, conductive and mixed with the same categories that we have used previously (i.e., mild, moderate, severe, and profound).

If you're reporting a unilateral loss, but you don't know what ear the loss is in, there's an ear unknown category. If you don't know the laterality of the loss, there's a field to report that in the laterality unknown.

We tried anticipating different scenarios that could occur when you have partial information. That's talked more in the explanations document. There's also a box included on here for auditory neuropathy where you can include cases for that.

There's no error checking built into part two, so it's not going to be tied back to part one. Again, the yellow fields at the bottom will be automatically calculated, the same principle as before.

You can click the "calculate totals" button near the top to see what the numbers are for those yellow fields, but you don't have to.

Moving onto slide 31, a couple of points related to type and severity. When you're reporting this data, if you've got data from more than one audiological assessment, please report it from the latest evaluation that occurred. If there was three evaluations, report it for the last one for type and severity.

Slide 32 also on the type and severity. This is similar to the previous DSHPSHWA survey. It lists the criteria used for this survey to define mild, moderate, severe, and profound losses. If your state or territory uses the same criteria system just click the "yes" option and proceed with the survey.

If you use a different system just click "no", and underneath in the bottom half of the table you will see blank boxes next to mild, moderate, severe and profound where you can input the ranges used. If you use different decimal ranges and different categories, just report those categories at the end of the survey, in the comments field.

Moving onto slide 33. After you've done all of this, if you go to the next link after type and severity, "review data", this shows you a summary of some of the key totals from the previous sections. This allows you to check to see if everything looks correct. This is important to check because once you submit the survey, you **can not** go back into the survey and resubmit new data. Once it's submitted, the data is finalized.

If you realize there is some serious error there with the data previously reported, please contact me and we'll figure out the best way to deal with that. But you can't submit the survey again through the web application.

After you look at that, you'll go to a finalized screen. This is slide 34, and it has a couple of bullet points there. We ask you to put in your name, your e-mail address, and put in your e-mail address again, the e-mail address that you put in is the link for how to get to part three of this survey. There's a drop down menu where you can select your state or territory, and you'll see that general comments field which I had mentioned previously where you can put in any comments you feel are relevant.

Finally, there is a red submit survey button, a link. Simply click that, and if you look at slide 35, you will get a pop up window just saying, are you sure you're ready to submit. This is just a check. If you are ready to submit, click on "okay."

As shown on slide 36, you'll get this thank you message, and my name, phone number and e-mail if you have any other questions.

>>**Minnesota:** A quick question. Do you have a feature someplace in there, we haven't seen it, where you can save it, you know, and not yet submit. It's saved so that other staff can go in and look at it and make sure we're all correct, versus just the person who started it?

>>**Marcus:** Unfortunately that's something we looked at doing but we are not going to be able to have that feature ready for the roll out.

>>**Minnesota:** I would strongly recommend it because we're going to   find in some of our state EHDI programs that different people have different parts of the data. Thank you.

>>Marcus: That's a very good comment, and we've certainly got it on our punch list, as it were for --

>>Unknown: This is also for data quality, double entry.

>>Marcus: Yes. What you can do in that situation, you can print out the printed copy from the web that has all the data items you're going to be requested to report on so before you open the survey, you can use that by sending it to the different people, have them fill it out.

>>Eric: So you can save it -- this is Eric from Kentucky. You can come back at different sittings or --

>>Marcus: Actually no. You would have to leave the application open. You can not close it and log back into it. If you close it without submitting, you'll lose everything that you've entered.

>>Cheryl: This is Cheryl in Georgia. If you start the survey, you need to finish it the day you start it?

>>Marcus: Yes.

>>unknown: How can you spread it around folks?

>> Marcus: Before you start the survey, if you print the adobe version from the web and ask people to complete this paper version. Once you get the information back from the various departments, you can then open the survey and manually enter the data.

>>Donna: This is Donna from Connecticut. Say we print out the survey, we fill out all the data fields on the paper. Have you estimated how long it takes to sit on the on line survey and complete it once you have the data?

>> Marcus: We found a range from anywhere from a few minutes to a few hours if you have pull all the data together. It would probably take 20 minutes depending on how fast you type and if you are entering all the data. The amount of demographics information being entered will affect the time involved as it is the longest part of the survey.

>> Stacy: I need to go backwards to the diagnostics section. This is my audiology brain talking. I was wondering if you have a recommendation of how we are to categories hearing loss in such distinct silos when we know that hearing loss is not just a flat mild loss or a flat moderate loss.

>> Marcus: You are talking about types of severity, correct?

>>Stacy: Yes, should we be doing it by the pure tone average. A lot of kids have sloping losses or cookie bite losses and it's not the same severity across the whole frequency range.

>> John: Yes. We can't solve all the problems, I'd go ahead and use PTA, pure tone average, if you've got it. At this age, that's tough to get.

>> Marcus: I want to finish up with the demographics part of this. On slide 37 it is just saying you've got to complete parts one and two of the survey before you can go to part three.

You come back to part three any time. You don't have to do part three at the same time you do one and two. Part three includes three demographic sections, demographics screening, diagnostics and intervention.

If you go to slide 38, this is the actual beginning screen of the survey of how you start part three. It's going to look similar to parts one and two, except it's going to ask you to enter your e-mail address. Please note you have to enter the **same e-mail address** as you did in parts one and two. If you entered jim@cdc.gov, that's what your state record is tied to. You have to enter that same that jim@cdc.gov address to access part 3.

Once you enter this, click on "begin survey." You will then see a screen shot (slide 39) of the hearing screening demographics table. Please note this isn't all of the items. This part uses that same menu bar at the top as parts 1 and 2. The page is highlighted in yellow. The fields at the top in yellow where it says totals, from part one, those are going to be the numbers that you entered in part one of the survey. For example, if you had 1,000 occurrent births in your state, that will pop up here.

You'll see the criteria here for reporting, for example, at "total occurrent births," you will be asked how many were male, and how many were female. There is also an unknown field. We know that the demographics part requests a lot of information. A key reason is because this is the data that is being requested for healthy people 2010. We know some states may not have all data available. We ask you just report as much as you can. For those states that are linked into your birth certificate, it should be easier to do.

I do want to point out just a couple of things here. I'm on slide 40 now. For mother's education, the information is only requested for those mothers age 25 to 50. So please don't report for mothers younger than 25 or older than 50.

For maternal race, there's an "other" category on the actual survey. Please use this to report any mothers that classify themselves as multiple races.

I just want to quickly go to the last slide, which is slide 41. This is the finalize screen. When you're done entering all your information, please go to the finalize screen. There will be a brief message, thanking you for completing the survey. There is also a comment field.

To complete the survey please click on the red "submit survey" button. You will receive that same pop up window as in part one asking if you are sure you are ready to submit. After selecting "ok" you will receive a thank you message.

This will be the end of the survey.

>>Luella: On the demographics screens are there going to be columns for age unknown like there were on the others?

>> Marcus: No. They are not needed because only demographic information related to "1-3-6" is being requested. The age unknown children are not apart of the demographics part.

>>Cindy: This is Cindy in Vermont. Once we have submitted it, can we print out the final version all completed?

>> Marcus: There will not be a formal or separate feature to do this so we are recommending that you print a copy of each section for your records. We should also be able to send you a copy of the data once you submit it.

>>Christie: This is Christie in Arizona. What is the due date?

>> Marcus: We are aiming for is whenever the survey goes out to have a four week turn around request time on it.

>> John: I want to add in here that the workings of the survey are -- the programming of the survey is actually essentially done. What we're dealing with is CDC security in terms of having outside people able to submit to the CDC, and that's what we're working on right now. And so we're working on that as fast as we can. Everybody has their it issues, particularly when it comes to security. We have the same things here as you do at the states and territories.

As I stated earlier, we know this is a little different than how data is be been reported, and how the numbers are probably going to change but what we've tried to do is level the playing field as much as we could so we could compare across states.

We appreciate as much as you can to fill this out. We know that probably no one can complete it completely fill out the survey in its entirety, but the more data you provide, the better idea we'll have of what's going on nationally.

>>Marcus: We are very well aware that all of you have very busy schedules, and we don't want to be burdening you with request for data that's not going to be used. Even though there's a lot of information on this survey, it was felt after a long review process that all of this information is important and it is going to be used by both CDC and HRSA.

So we hope this will help cut down on multiple data requests. We're hoping to really have the majority of the information in here so the least it consolidates it. S john said, we know that you might not be able to complete all the survey. We're very well aware of that, especially in the first year. The survey represents a standard of where to move towards for the amount of information to be requested and how it's going to be reported.

If you have any questions please let us know. We also want the feedback

>>Molly: This is molly from Indiana. I have a quick question about the -- on the screening page typically our hospitals screen prior to discharge. What do we do about those transferred babies? That's a number we don't have a handle on as to when they're screened.

>> Marcus: You can report under total passed and total not passed, there's an age unknown option. If you know a child was screened and they passed, but you don't know when, you can report them in the "age unknown" field.

>>Molly: If we have a good guesstimate as to how many were in NICU and that they were later, we could put that number there?

>>John: Remember that if you put them under not passed, you'll have to account for what happened to these children in the diagnosis section.

>>Molly: So it would be passed. I just won't know what --

>>John: There's a "passed: age unknown" field that can be used.

>>Marcus: If you don't know they were screened there' is a missed category.

>>John: If there are no other questions, thank you all for tuning in. We very much appreciate you spending your time with us today. I don't think there's a special topics in March because of the EHDI conference. Hopefully we'll see you all there.

>>Marcus: Thank you everyone.

[END OF MEETING.]

Roughly Edited Transcript