

Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Teleconference
April 26, 2005

Presentation:

EHDI Border Babies

TO: Ad Hoc Group for EHDI
FROM: Jamie M. Elliott
SUBJECT: Conference call information and agenda.
DATE: Tuesday, April 26, 2005

The EHDI Border Babies teleconference took place on Tuesday, **April 26, 2005** from **3:00 to 4:00 pm Eastern** time. If you have any questions please contact Jamie Elliott (jei2@cdc.gov / 404-498-3018) or Marcus Gaffney (Mgaffney@cdc.gov / 404-498-3031).

Agenda

1. **Welcome**, Jamie Elliott, CDC EHDI
2. **General Overview**, Marcus Gaffney, CDC EHDI
3. ***Regional Bias in Birth Defect Prevalence Rates for Arkansas: Influence of Incomplete Ascertainment Along Surveillance System Borders***, Bridgit S. Mosely, Arkansas Center for Birth Defects Research and Prevention
4. **Legal Issues**, Beverly Peoples, CDC Office of Science Policy and Technology Transfer
5. **Data Implications**, Craig Mason, University of Maine
6. **State Perspectives**
 - Jessica MacNeil, Epidemiologist, Universal Newborn Hearing Screening Program, Massachusetts Department of Public Health
 - Julie Schulte, State Audiology Coordinator of UNHS EHDI, Indiana State Department of Health
 - Sue Burns, State Implementation Coordinator, Children's Special Health Services, North Dakota Department of Human Services

Topic Abstract

EHDI Border Babies are infants and children who receive hearing-related services at a facility located in a state other than the state where the infant was born or currently resides. Following EHDI Border Babies to ensure that recommended hearing screening, evaluation, and follow up services are provided in accordance with EHDI National Goals can be very challenging. While no standard currently exists for sharing information on EHDI Border Babies, some states have developed formal and/or informal systems for sharing EHDI Border Baby information across state lines. This teleconference will provide an overview of the issue and highlight some of the ways that states are sharing information on EHDI Border Babies.

Edited Transcript

Jamie Elliott: Good afternoon, everyone. It's 3:00 so we will get started. First, I'd like to welcome you all to the teleconference and I'd like to thank our speakers and all of you for calling in. At this time, I ask you to please mute your phones when you're not speaking. If you need to leave the call, please hang up and call back in. Please do not use your hold button while on teleconferences. We've had music in the past. If you need to leave the call, please hang up the call and dial back into the call when you're ready. This afternoon, we have a very full call planned.

This afternoon, we have a very ambitious call and very ambitious agenda and some very knowledgeable speakers to address the issue. Our first speaker is Marcus Gaffney, who will provide an overview of the issue. Marcus, are you with us?

Marcus Gaffney: Yes, hi, Jamie. Thank you.

Jamie Elliott: I'm going to do a brief introduction. Then we will get started with Marcus. Marcus has his degree in public health from Emory and worked with us for several years now. Many of you probably know him. Recently Marcus has been working with CDC staff on states in the New England area on what we call the New England border babies project.

Bridget Mosley is currently a master level epidemiologist. She serves as the assistant Scientific Director for the Arkansas Reproductive Health Monitoring System (ARHMS). Bridget got an MPH at Emory University in Atlanta where she concentrated her degree in Epidemiology and Women's Health. She was an epidemiologist at the Arkansas Department of Health and will speak to us about border issues and their impacts around birth defects.

Beverly Peoples of the CDC office of science has extensive knowledge of HIPAA and FERPA issues and today she is going to answer some of our questions about the legal issues surrounding EHDI border babies. She will be followed by Craig Mason of the University of Maine, who will discuss data implications of the Border Babies. Finally, representatives from three states will offer their perspective and their situation regarding EHDI Border Babies.

Speaking for our state will be Jessica McNeil, an epidemiologist in Massachusetts. Sue Burns from North Dakota will also be speaking with us. She's the state implementation coordinator for the first sounds early hearing detection and intersection program. And Julie Schulte from Indiana will be speaking about the UNHS program in Indiana.

With that I'm going to turn it over to Marcus Gaffney, after first letting you know again some of our presenters do have PowerPoint presentations that you can follow along with and these are located at www.infanthearing.org/checkpoints/CDC. Again, please make sure your phones are on mute if you're not speaking and please don't put your phones on hold. Instead, just hang up and call back in. With that, I will turn it over to Marcus to get our call under way.

Marcus Gaffney: Hi, thank you, Jamie. Good afternoon, everybody. I wanted to take a couple of quick minutes to frame a general overview. EHDI systems have been undergoing continual development over the last few years. There's increased emphasis on making sure that all children receive recommended services related to hearing, to make sure that those with hearing loss are identified as soon as possible. And part of the process of making sure all kids receive services is addressing this so-called EHDI border baby issue. I think this is an issue which we've been interested here at CDC for a while and we've been actively working with a small group of the New England states for several months now, just trying to find out a little more about this issue and how some deal with it. I think today's call should be a wonderful opportunity to learn more about what's going on across the country, some of the legal implications of this and some of the data implications, also. Danielle, did you want to add anything?

Danielle Ross: Yes-- the two main reasons that alerted us to this issue and got us started on focusing on it, were that we wanted to be able to follow up on the individual children themselves, and, if we want to have accurate surveillance, we need to have the right denominators and the right numbers in terms of how many children are being followed up. So that was the second main reason that we became interested in this. So, Jamie?

Jamie Elliott: Thank you, Danielle and Marcus, for the brief overview. Bridget Mosley, are you on the phone with us?

Bridget Mosley: Yes, I am.

Jamie Elliott: Wonderful! I'm going to turn it over to you to talk about your study.

Bridget Mosley: Okay. I just want to thank everyone for the opportunity to be a part of this discussion. And basically what I wanted to do is just kind of share our experiences and the activities we've been doing here in Arkansas with our birth defects surveillance system in addressing this issue of, I guess I'm using the term border bias here, but I think we're talking about the same phenomena. I do recognize that the methods that we use with monitoring birth defects may be slightly different from the methods that are used for monitoring newborn hearing, especially when you're attempting to do the monitoring of the follow-up services. But what I hope maybe is that just by informing you of some of the processes and activities that we've gone through, then maybe you can use that information.

I wanted just to start briefly and tell you the how we conduct our surveillance of birth effects in Arkansas. Our surveillance is called the Arkansas reproductive health system. We call it ARHMS. It's relatively mature as far as the system is concerned. It's been in operation since 1980 and it uses active surveillance methods, meaning that our staff are given access to hospital discharge information and any medical records that they request are made available to them, and then our staff will determine who is eligible for the surveillance program and abstract all the needed information from the medical records. The ARHMS has started as just a system that monitored central Arkansas, but it went statewide in '93. And so it's been operating as a statewide system since that time. And in order to be included as a case subject for ARHMS, a child has to have had a birth defect diagnosed prior to the ages of 2 and/or the pregnant mom has had a diagnosis of a birth defect. An additional criteria is that the mom must be an Arkansas resident at the time of her delivery or in the case of a prenatal diagnosis at the time of that diagnosis. Then the state legislation gave ARHMS the authority to get access to all of these medical records and hospitals, but, of course, that's limited to hospitals that are located within the state, and we all know that people don't necessarily stay within their state borders when they're seeking their healthcare.

Arkansas is one of the landlocked states. We share a border with six other states, which means we have at least six different scenarios that we have to deal with when we talk about getting access to information across the border. And I don't know a lot about the standardization of the newborn hearing screening programs or hearing surveillance programs, but I know that with birth defect surveillance, there are no standardized practices that a state is required to follow.

What we're doing here in Arkansas is not necessarily what any of the other states are doing and I think that, as I talk about more of our successes, that comes back to be a really important issue. ARHMS does have similar surveillance methods as two of the states it borders: Texas and Oklahoma. And it just so happens that those are the two states where we have some form of agreement currently in place where we can share data. And with Oklahoma we have a informal agreement with the state's birth defect program to exchange data that either of our staffs identify in the field or at some point, if we're matching to a birth certificate, we identify as a Oklahoma birth, then we will actually exchange the data that either one of us collects.

And with the agreement we have in Texas, it's kind of a unique situation. We have access to two hospitals that are located in Texarkana, Texas. Texarkana is a border city. Half of the city is located in Arkansas; half the city is located in Texas. And I believe the mindset down there is pretty much that they serve both residents of Arkansas and Texas, and the hospitals allow us access to their records, just as if they were located on our side of the border. Both the agreement we have with Oklahoma and with the agreement we have with the Texarkana hospitals, they are informal, meaning we don't have any official document in place to regulate those agreements. It's just been with the age of the surveillance system, it's been, you know, probably an agreement that's been in place for 10 to 15 years. It's prior to all the HIPAA, FERPA, or any of the confidentiality concerns and so there's both some good and bad with having these types of informal agreements. I know in the past I've been asked whether, you know, I fear that someone was just going to pull the plug on those agreements and I think that that's a real fear that we have at times, because we don't have anything formally in place and, you know, somebody from either side could just all of a sudden decide they don't want to do this anymore. But what I do think helps us with maintaining these agreements is both in Oklahoma and in Texas the birth defects surveillance systems are very similar to ours. They have staff that are going into those hospitals and doing exactly the same thing we are, collecting data on their individual states.

So, from the hospital perspective, if a person has TX or AR on their name tag, it really doesn't matter to them because we're all doing the same thing there. Now, what I did want to get to was some of the research that we've been doing, and actually it's way along the other side of our state, in the northeastern part of the state, where we had a big concern that we were missing quite a few cases that were eligible for ARHMS who were Arkansas residents but were seeking healthcare in the Memphis, Tennessee area. There are great hospitals, including a rural pediatric specialty hospital. So, we were very concerned that we weren't getting access to that information and weren't being registered in our surveillance program. And so we basically designed this study where we could estimate any difference in the actual counts of birth defects in that area, compared to what we would have expected and we measured the impact that this would have on our birth defect rates, both for overall defects and for specific groups. And it first started with using some bio statistic data, which actually is a system that has some standardized practice and they do have a formal data exchange agreements across all borders so we turned to that system to first sort of give us an idea of the pattern of healthcare use of our Arkansas residents and then we also used that data to try to identify a comparison population so that we could calculate expected rates.

And we selected a comparison population and designed our study so that we could control for social economic factors, race, and maternal age, which are all important factor as far as birth defects are concerned. The bottom line is that what we found when we conducted this study is that each year we are probably missing at least 100 birth defect cases that are eligible for ARHMS. That number is probably a low estimate just because of how we had to define our geographical area, but it was making a major impact on our prevalence rates and more so for our race-specific rates, where we saw that we're probably underreporting African-American race by about 12% and underreporting the race for whites by about 4%.

If you have access to the slides, you can see there's a citation there where you can get to the published manuscript, so, if anyone is interested in more details about that study, then they can get to it by looking at that citation. Anyway, we have used the results from this study for several purposes. One, we made sure that the Tennessee birth defect surveillance program got a copy of it right away and we have used it with similar types of discussions as we're having here today when we talked with other birth defects surveillance programs, and we also use it anytime we're doing our research, where we're reporting prevalence rates or looking at geographical location as a risk factor for birth defects.

We refer back to this study knowing we're underreporting what we're defining in that area. Some good news is that in January we got a commitment from the Tennessee birth defects surveillance program to exchange data, and I'm drafting a document now so that we can have a formal

agreement with them in place to exchange the relevant data that each of our programs may need. There's still a lot of work to do as far as that arrangement is concerned because the Tennessee system is a passive surveillance system, meaning that they're relying on the hospitals to report their information and their staff isn't given access to as much information as an active surveillance program would be. But still, though, you know, we're hoping to build off of this and build the relationship, both with the surveillance program and hopefully at some point, maybe even with the hospitals in the Memphis area and move things along so that we can continue to try to get access to some of that data that is being gathered by those hospitals. So that's just a quick overview of what we're doing in Arkansas.

If anyone has questions or comments, I will be glad to take them, either on this call, I don't know if we have time on the call, but you can certainly contact me, and I will be glad to talk with you more if you have more questions.

Jamie Elliott: This is Jamie Elliot at CDC. Thank you very much for the presentation. I think it will be applicable in many ways to what we're going through with EHDI. If you have questions, I'd ask you to please e-mail Bridget Mosley. I think in the PowerPoint slides is your information included.

Bridget Mosley: If maybe - I don't know if I got it on there. I can give it to you if you need my e-mail address.

Jamie Elliott: Would you be willing to share it?

Bridget Mosley: Yes, I sure will. It's just mosleybridgets@uams.edu.

Jamie Elliott: Thank you so much. Beverly peoples, are you with us?

Beverly Peeples: Yes, I'm here.

Jamie Elliott: Wonderful. We've invited Beverly to speak today about some legal issues and I think she may take your questions right away.

Beverly Peeples: Okay. Well I did receive an e-mail with fundamental overarching questions and some issues that I'd like to address, and then I'd be happy to take questions from anyone who would like to ask me. First of all, I'd like to clarify, and I'm sure most of you are aware of this, that the HIPPA privacy rule really does not address the issue of state health departments or fundees of CDC, who are doing surveillance sharing data, whether internal, into a state, or within entities or interstate -- intra or interstate, between states. Certainly there are always state law issues and, as you all well know, privacy laws and medical sharing, medical information sharing laws do differ from state-to-state and that really is --

I'm sorry. But the state law -- state law is really going to be the major legal impediment to sharing data between states and programs when you're talking about border baby issues. We've worked even internationally with the Brownsville border project with birth defects surveillance between the 2500 miles; I believe it is, border area between the United States and Mexico. Even on an international level, the issue is state and local law but even more than that is the actual perception that has been raised or the issue that has been raised by the awareness of the implementation of the privacy rule, that sharing data is a concern. And as the previous presenter stated, very often you can make these arrangements informally. However, you do risk the possibility that you get a new administrator or a new individual in a certain position who says wait a minute; we're not going to do this anymore. Of course, institutionalizing your data collections and data sharing in a formal, written MOU or agreement is a good idea. From that perspective, although it's certainly not required by the privacy rule, it may be required by a state law. However, sometimes it's easier to get an informal agreement than it is to get a formal MOU.

I'd like you to know that my office here at CDC, the Health Information Privacy Office, provides technical assistance on writing MOUs between CDC-funded programs and states, and does work on a regular basis with the health department attorneys and state attorney generals on letters of agreement and MOUs. So, if a state does need that type of assistance, you're certainly welcome to contact my office for that type of assistance.

The other issue is the question about whether -- one example that was sent to me, it's the example of metabolic screening and sharing, that type of data. And how it's provided on border babies because it is a so-called *matter of life or death*, compared to a hearing loss, which is a so-called *developmental emergency* or *developmental issue*. And really the Privacy Rule doesn't address, as public health surveillance and intervention, whether or not something's an emergency or a matter of life or death. In other parts of the world it does, but not when it comes to public health surveillance and intervention, which developmental delay and developmental interventions are public health activities -- considered public health activities, under the Privacy Rule. So, I guess with that kind of basic foundation in place, I'd be happy to take anyone's questions.

All right, it sounds like -- does anyone have any questions they'd like to ask? Or did I just confuse everyone beyond compare?

Jamie Elliott: All right, well thank you very much, Beverly. That was very helpful. Craig Mason, are you on the line?

Craig Mason: Yes, I'm right here.

Jamie Elliott: Wonderful! Could you speak to us about data implications?

Craig Mason: Sure and I'll try to go quick so we have time for the three states. I partially wanted to emphasize, from the data angle, is the need to start to -- for programs to consider this and consider border babies in their program design and work. Particularly in the areas of lost follow-up and potential system-added bias in the numbers that we're reporting, but also, as a method of more reliably being able to pool data across states or regions. Plus, the potential impact on long-term follow-up as we increasingly start to think of down the road, following kids several years out.

In terms of the potential follow-up and systematic bias, Bridget has already talked about this notion of geographic isolation or proximity resulting in kids in the border baby issue of babies being seen outside of their state of birth, but you can also see border baby issues arise from more of a service usage issue that babies may go to a different state for diagnostic testing or cochlear implants -- I keep getting beeps! -- or other types of service. The concern, particularly in the latter, is that it can introduce real systematic bias in the numbers that we're reporting. For example, you know, we may think that, well, the actual numbers of babies that we're talking about may only be a few hundred -- you know, if you're a state with 30, 40,000 births, it may be only several hundred kids, which is, you know, less than maybe 1 or 2%, if that. But if it turns out that the babies that are going out of your state are also the ones that have been identified as at-risk or have other risk factors that may lead them to some other regional hospital for a delivery or they may be going outside of your state for cochlear implants, and then follow-up and care. A small number of infants could, in fact, reflect a relatively large percentage of the actual kids we're ultimately following up, who have the hearing loss. So, we want to think of it not just in terms of how big of an issue is this relative to the total number of births, but the actual number of children out there with hearing loss and how are these babies impacting those numbers?

Again, it may seem like it may not be a whole lot of children, but if it allows us to reliably pool data across states that can be a big benefit in terms of, if we're trying to combine data. Referring back to Marcus's discussion of the New England states, you know, pooling data across several smaller states reliably can really have a significant impact in our opportunity start talking about estimates of both prevalence and potential risk factors down the road.

Finally, there is an issue of long-term follow-up that we need to increasingly be focusing on as we're looking at following kids, not just from screening to diagnosis, but into service delivery and ultimately into some long-term developmental outcome data. Every year there will be more and more babies and children and families that are moving from one state to the other, and this will have an impact on a much broader area than just immediately neighboring states. But we will need to increasingly start to address the overall issues of migration of families as we start to enter school age kids down the road.

The -- a couple of things really quickly in terms of the -- in a practical perspective trying to do this -- we've already heard discussion from Beverly about the political issues of state law, which can be, of course, obviously a significant issue. And both, you know, just a few points in some of the talks from the states that we're about to hear, is looking at some of the ways states are trying to tackle the issue from a data perspective. For example, I think we will see that Massachusetts and Indiana deal with the border babies stored in different places and think, you know, where is the data that may exist for kids outside of your state? It is ultimately vital if we're going to try to find where these children are. So with that, we still have half an hour, I will wrap that up. You can contact me if you have any questions. But let's move on to the states.

Jamie Elliott: Okay, thank you for that! We have three states offering perspectives today. We begin with Jessica McNeil at the Massachusetts Department of Public Health.

Jessica McNeil: Okay, thanks, Jamie. I would like to begin today by giving a brief overview of the universal newborn hearing screening program in Massachusetts. Then I will discuss our current procedures for working with families of border babies and what we would like to accomplish in terms of data sharing for these infants. In Massachusetts, there are approximately 81,000 births annually. Roughly 2400 of these children are residents of neighboring states, who are born in Massachusetts, and there are an additional 1300 Massachusetts residents who are born out-of-state each year. We have 53 birthing facilities all of which have newborn hearing screening programs. By law, the hospitals are required to refer any child who does not pass their hearing screening to one of 26 approved audiology centers. In Massachusetts, residents with hearing loss are eligible for early intervention services, and we currently have 70 early intervention programs in the state.

In August 2004, CDC EHDI staff conducted a regional site visit with all the New England states. At this site visit, border babies were identified as a concern for all the participating states. This led CDC EHDI staff to participate in the Massachusetts diagnostics in their staff meeting, were representatives from each state, approved add logical evaluation center to discuss the issue of border babies and made recommendations, which I will discuss later. Then, beginning in 2004, a series of monthly conference calls began with the CDC EHDI staff and representatives from each of the New England EHDI programs, to identify ways to address the issue within the New England region. This group also had a brief discussion during the regional workshop at the 2005 National EHDI Conference.

I'm now going to discuss our current efforts for providing help for out-of-state residents born in Massachusetts. The hearing screening results, due to the electronic birth certificate, for all babies born in Massachusetts, including results for babies residing out-of-state that are born in Massachusetts. We ensure that all families whose newborn did not pass the screening get follow-up testing. Legally, we don't have the ability at this time to share results with the home state of the child. However, if a child receives diagnostic testing in Massachusetts and the parent gives consent, the home state will be notified of the results. For Massachusetts residents who are born out-of-state, we receive an electronic birth certificate, which provides program staff with some limited demographic information and outreach staff uses the information to send letters to families to be sure they receive the hearing screening at birth. The letters provide our phone numbers and e-mail address for the parents to respond to. We currently only have a response rate of 33% to do this. And 1% of the system is the information we received from the electronic birth

certificate is not timely. Children are already several months old when we are notified and that makes follow-up more difficult and they are also coded with mis-screens in the birth certificate.

So, to briefly summarize, our program staff provide follow-up on screening results for all babies who are born in Massachusetts or who are Massachusetts residents. However, there are limitations within this system, which we hope to resolve with this current effort. I will now discuss our diagnostics and procedures related to border babies in Massachusetts. The state approved audiological evaluation centers always send us programs. And all children born in Massachusetts, as well as Massachusetts residents who are born out-of-state, if audiological follow-up occurs in Massachusetts. We don't have a way to accurately determine the number of out-of-state children receiving follow-up in Massachusetts, our audiologists estimate that the number of out-of-state children who are seen or followed annually in the center ranges from a few children to a couple of dozen children. At the diagnostics and their meeting at CDE EHDI staff participated in, this year border babies was discussed. It can be difficult connecting families to resources in other states.

Therefore, they agreed to report diagnostic reports with informed consent to other New England EHDI programs to other out-of-state programs who are seen in their centers. It is determined that centers would use the Massachusetts tracking form and fax it to the EHDI contact in the state where the child lived and there was consensus that it could help connect families to services in states that reside in. Centers agreed it would be manageable since they don't see a lot of out-of-state children. Since the diagnostic results on out of state children are now being reported to their home state EHDI program, the goal of the current program from Massachusetts is to develop a system to receive screening results and limited demographic or contact information for all Massachusetts residents born out-of-state in a timely fashion and provide the information to other states for their records.

Right now, the biggest challenge for Massachusetts in this effort is a state law called the Fair Information Practices Act or FIPA. It requires us not to disclose personal information without consent, except in very limited circumstances. There are no exceptions for sharing information for treatment purposes. There is no state statute prohibiting receipt of it from other states, but an amendment will be required to share data with other states. We're currently working with our legal process to begin the process of writing this amendment. An additional challenge in New England is that everyone doesn't use the electronic birth certificate to populate their database. Even if FIPA wasn't an issue, we couldn't just amend the birth certificates between states. And the information we get from the birth certificate on Massachusetts residents is not timely for out-of-state births and the children are already several months old when we are notified. So, to wrap up, our next steps in the effort include continuing to work with our legal office to amend the Fair Information Practices Act and to determine if there are other legal challenges that we will have to address. We will also continue working with the New England border babies work group to develop a list of common day items that will be shared between states once we are able to move forward and we will also work to develop a memorandum of understanding with the other New England states and finally, we will continue to explore other state's procedures related to border babies to determine if there are any documents or processes that have already been created that may help in our effort. Thank you.

Jamie Elliott: Thank you, Jessica. Julie Schulte, are you on the line?

Julie Schulte: I am.

Jamie Elliott: Wonderful! Julie is with the Indiana of Department of Health. Please go ahead.

Julie Schulte: I'm sorry, I had to join the call late, you know, with the change of time, Indiana can't quite get what is 3:00 on the east coast and what's 3:00 here! So, anyway it was nice of Marcus and Jamie to invite me to talk today. I said are you sure you want me to talk? Our state's follow-up is not perfect, but we're certainly working to improve that on a daily basis. So, I thought

I would start by just giving a small history about what's happening with UNHS in Indiana. Our law here was passed in 1999 and then all hospitals were in compliance by July of 2000. So, you can see on the second slide that really by the end of 2000 we had all of the hospitals within our state, who are in compliance with universal newborn hearing screening and that was about 102 facilities then, and we are currently up to 109 facilities across the state of Indiana. And they can use either OAE or ABR or a combination of those two pieces of equipment.

In terms of our statistics, you can see on the next slide, that we, in 2004, we don't have the final numbers, but we had around 87,000 live births in our state. We had 11.1% who didn't pass the initial screen and all received their follow-up screening, and then a total of 3.7% were referred after the second screening or not passing the second screen. And the babies in Indiana can be referred one of three places, if they do not pass. They can be referred to first steps, which is our early intervention system. They can be referred to their primary care physician, and they can be referred to an audiologist directly or EMT directly. They can receive one of those referrals or all three of those referrals. And then we had about 0.6% of our babies referred for risk factors. And again, the babies can receive the same kinds of referrals, either to first steps or prevention, primary care physician, or to ENT audiology directly.

Go on to the next slide, and what we do for our follow-up is first of all, whenever a baby does not pass the second screening, an automatic referral is to go to our early intervention system, and that is to be done via a fax. So, the first step system receives a fax and within 48 hours of receiving that referral, they are to contact the family and set up follow-up testing, diagnostic testing. That's in an ideal world. We know that that doesn't exactly happen 100% of the time. We know that in some locations that families are not contacted by the first step system. And in some instances, families are referred but they're not necessarily referred to centers that can complete the diagnostic process, which I know that most states have that issue. At the Department of Health, we do have a letter campaign that we do for all babies who do not pass and also babies who are not screened and also babies who are at risk. And the way that the Department of Health here currently gets our information is that each hospital is responsible for sending in what's called a monthly summary report or MSR. So, we get 109 of those in a month, and they're due the 15th of the month for the previous month's data of births. And once we receive that information, our chief nurse consultant here looks over the data, and we enter that into our database Intel, which is a free-standing access base system that was designed here in Indiana.

And then we begin our letter campaign. And in a perfect scenario, we would send out our initial letter in 30 to 45 days following birth and that letter will go -- two letters go, one to the mother and one to the primary care physician. And as I said in a wonderful world, it would happen within 30 to 45 days, but as I mentioned, with the MSR, or monthly summary report due the 15th of the month for the previous month's data, babies can be already 30 to 45 days of age before we receive the information here at the Department of Health, and then it has to be checked and entered into the system. So, we also have the problem that oftentimes our letter generation does not begin to occur until the baby is at least 45 days of age, sometimes longer than that, maybe a couple of months of age. After sending the initial letter, a second letter will go out, approximately two weeks after the first letter and the letter -- two letters, again, will go out. One will go to the mother of the child, again, and then the second letter will go to the public health nurse in the county where the child resides. We also try to do phone contact but, of course, with just three of us here at the Department of Health, and only one audiologist here, it is difficult and very time consuming to make telephone calls. So, we do try to do that, although we don't always get to that in a timely manner, as well.

For babies who are at risk for delayed onset of hearing loss, we do a letter campaign with them, as well. The initial letter goes out at 5 months after birth, in hopes that the baby will have the letter and the mother will take it where they go to their six-month appointment with their physician and, again, we send a letter to the physician, as well. And then the second letter goes on out for babies of delayed risk of onset at about 9 months of age, in hopes that the baby or the family will

have the letter in time for the 12-month appointment and can take that with them. Again, we try to do phone contact with these people, as well. And then in terms of our audiologic or diagnostic follow-up, we have a form here in Indiana called the Diagnostic Audiology Evaluation (DAE) Form, which audiologists are recommended or requested to fax or mail directly to the Department of Health, when they see any child who has been referred from UNHS, whether they didn't receive a screening or were at risk or didn't pass.

Unfortunately, this form is a voluntary method of reporting so oftentimes we don't get those. We have received many, many of them. We have over 4,000 of them in our database over the last two years, but, again, we don't get them from I don't know what the portion is, of audiologists, but we're still missing a lot of DAE forms. And then also, if a child is being followed through the First Step system, as we've talked about the privacy issues that we do have difficulty with exchanging information with our first steps program, and we are in the process of developing a protocol so that each family who has a child identified with hearing loss and even those babies who are just generally referred from UNHS, that a consent form will be signed by the family to enable First Steps to provide the Department of Health with follow-up information. And we may also take on the responsibility of doing the follow-up letter generation because we can do that automatically, whereas the First Steps early intervention system has to do that all manually and so if we can collaborate a little bit better, I am sure we can make our program a little bit more efficient.

So, in regards to border babies, -- with babies who are born in Indiana but reside in bordering states -- we have four bordering states. We have Illinois, Michigan, Ohio and Kentucky, and regardless of the state of residence, we do complete the follow-up that was mentioned previously, although we do have difficulty with public health nurses and so typically we send out the letters to the parents and the physicians. If we haven't heard anything by the second letter, we send the **less list** to the # EDHI contact in the home state. And we do have an informal agreement with the states around us that we will send that information, although we have been exploring the plan that we need to develop a more formal MOU with the states around us. Babies who are born outside of Indiana but reside in Indiana: Currently what's happening, you can see on the slide, is that Illinois is currently forwarding us the names of the babies who do not pass or have risk factors and also those who are not screened so that we can help with the follow-up and tracking of those babies.

Ohio also is currently forwarding us babies who do not pass or have risk factors. And then Michigan and Kentucky are not currently routinely sending us information, although once in a while that does happen, and I understand from Michigan and speaking with them that their system is not really up and ready yet to be able to do that automatically. And in Kentucky, their law requires that they do the follow-up and tracking regardless of where the baby lives. In terms of our database, which Craig mentioned earlier, the babies who reside in Indiana but are born outside of Indiana, we do not put those in the same part of our database as the babies who are born in Indiana. So, they are separated so the data that we report to EHDI and to CDC, we do separate those numbers. So, we don't add them to the UNHS overall numbers, we don't add them to the numbers of the baby -- excuse me, the proportion of babies who are screened prior to three months of age or evaluated prior to three months of age and don't count them in the number of babies who are identify with hearing loss ultimately. We do count the babies for the number of babies who are receiving early intervention services by six months of age because there's no way for us to tease that out of our early intervention data at this time. It's possible that that may change.

As I mentioned, we are trying on a daily basis and one of the big changes that's going to happen and has begun to happen in Indiana is that our UNHS data is going to become part of the new blood spot card. The cards went out to some hospitals beginning in January of this year and more and more hospitals are beginning to use them and the lab within our state that handles all of the metabolic screens is also creating a new database system. And so they will do the majority of the data entry for us and they obviously get the information in a more timely manner, by the time the baby is just a couple of days old, and do get the data into their system by the time the baby is

a couple of weeks old. So, it would be feasible for us to learn about a baby who did not pass or wasn't screened or had risk factors at the time they're just a couple of weeks old. We're ecstatic that's coming down the pike very shortly for us. And I think that that is all from Indiana.

Jamie Elliott: Alright, thank you very much, Julie. Sue Burns, are you on the line?

Sue Burns: Yes, I'm here.

Jamie Elliott: Could you talk to us about North Dakota?

Sue Burns: In North Dakota, we're small in numbers but large in size. We only have about 9,000 births born in our state each year and that includes those out-of-state babies born in our North Dakota facilities. We have about 1,000 out-of-state border babies, born in our state. We currently have 23 hospitals that all do hearing screening prior to discharge. We have a web-based tracking system that all hospitals have access to, as well as the state program, where they can enter data on when the baby is screened. We are able to collect quite a variety of information, such as, the basic demographics, screening results, screener, hospital, that type of thing. We do monitor and we collect this data on all births regardless of their state of residence.

Jamie Elliott: Sue, if I could interrupt for just a moment, just a reminder to everyone, please mute your phones if you're not speaking at the moment. We're getting background noise making it difficult to hear. If you don't have a mute button, you can hit star 6 and that should mute you. So, pardon the interruption. Thank you.

Sue Burns: That's okay. Basically we treat our border babies as we do our in-state babies as far as screening goes. Some of our restrictions or flaws in our program, occur if a facility is not good about completing all of the data. A contact is made to facilities to request they include all the data fields. Every two weeks the program will query the infants that did not pass the hospital screening. The families will receive a reminder letter requesting they follow up on that newborn screening and have the hearing rechecked. If the infant is re-screened at the hospital, the hospital staff can enter the re-screen data on the web-based tracking system.

We also work with a variety of local community providers. We would like our community partners to ask families, whenever they come into their offices, to ask about newborn hearing screening results and encourage the families to have the hearing loss re-screened if they did not pass at hospital discharge. We also ask them to refer any infant into programs that can assist them in accessing services. In North Dakota, we have four diagnostic audiology centers. They're located regionally in the four quadrants our states. Two of them are on the east border, which is where the majority of our population is located. Fargo, which is our biggest city, is on the border with Minnesota. The majority of our out-of-state babies are from Minnesota. Fargo MeritCare is a diagnostic center for North Dakota as well as for southwestern and western Minnesota. They have the forms needed by Minnesota to notify them of a child diagnosed with a hearing loss. Whether we refer those Minnesota babies for an audiologic evaluation or Minnesota has actually seen them in one of their screening hospitals and referred them to the North Dakota diagnostic center, Minnesota will receive information on one of their forms that they've developed. We still have a lot of work that needs to be done. We do not have formal agreements with any of our bordering states. We have had conversations with the Minnesota folks on what needs to be done, and we're looking into some of those options. So, it's definitely on the table and moving up on the list to get done. We do have a web-based tracking system, which could be accessed in the diagnostic centers. We are also considering a new process where we would partner our diagnostic audiology centers with a coordinator from the school of deaf so that whenever a family comes in to have a diagnostic evaluation, the school for the deaf coordinator will come with them. The coordinator can provide assurance to the family and also be a resource to the audiologist. The coordinator may be able to enter the data on the web-based system as that seems to be an issue.

[Inaudible]

We're hoping this will be a new area where we can see some improvement from our audiology centers in the reporting of their data. I would also mention North Dakota does not have a state mandate for screening or reporting. We are looking at it in our next legislative session, possibly expanding on our law that require mandatory reporting of certain birth defects. So, that's basically where North Dakota's at right now.

[Inaudible]

>> Okay.

Jamie Elliott: Thank you, Sue. With that, we have a few minutes left, about five minutes, and I want to open it up for questions and these will be questions for any of our speakers who are still with us. So, I'm going to open the floor. And first I want to thank all of our speakers for your presentations and for talking to us about your programs and what you have been doing with this issue. So, I'll open it up for questions.

Minnesota Participant: I have a question for Indiana, this is Minnesota. How are you forwarding information to other states? What kind of means do you use?

Julie Schulte: Just regular mail. We print out, from our database system, the basic identifies information from the baby and the reason for their referral and then send that via mail to the EHDI contacts in the states.

Minnesota Participant: So, you use postal mail?

Julie Schulte: Yes.

Minnesota Participant: Okay. Although you don't have formal agreements?

Julie Schulte: No.

Minnesota Participant: Okay. Thank you.

Julie Schulte: Uh-huh.

Vermont Participant: This is Vermont with a question for Indiana, also. I was just wondering if you know off the top of your head how many risk factors you're screening for - for delayed onset hearing loss?

Julie Schulte: Good question.

Vermont Participant: The reason I ask is I'm trying to figure out if 0.6% is what we should be expecting, is it greater, less...

Julie Schulte: Gosh, I wouldn't even guess about that, but I would guess that the risk factors should be greater than that. But we are using at least eight risk factors.

Vermont Participant: Okay.

Julie Schulte: Yes. And we continue to do training, obviously, with hospitals and with audiologists, and the audiologists are pretty good, of course. But the OB and nursing staff sometimes at the hospitals really have a hard time with this at-risk factor so we know with one facility that sometimes children get referred and they're said to be at risk and they're really not at risk. And then in other facilities, babies are not routinely being referred and they are at risk. I would say our number is not accurate, but I don't know how far off it is.

Vermont Participant: So, you get the risk factors from the birth certificates or from the -- from your audiology report form?

Julie Schulte: Currently the way we get that is simply on our monthly summary report. They will be listed as at-risk for delayed onset of hearing loss, but we don't know which factor is actually making them at risk. When we get a follow-up diagnostic audiology evaluation form from an audiologist, that will have an indication exactly what the risk factor is.

Vermont Participant: Oh.

Julie Schulte: And when we go to the blood spot card with UNHS data on the blood spot card, again, it will just say does the child have risk factors, yes or no, but we won't know exactly what risk factor that child falls under.

Vermont Participant: Uh-huh.

Julie Schulte: Yes, we know it's not perfect!

Jamie Elliott: We have a couple of minutes left. Any other questions?

Washington Participant: Hi, this is Washington. I have a question for Bridget Mosley. How do you exchange data with Oklahoma and Texas and those other states? Is she still on?

Jamie Elliott: Bridget, are you still on the phone? -- She is not. I can forward you her e-mail address if you'd like.

Washington Participant: Okay. And then I had a second question for Beverly. What CDC office would help with the MOUs?

Jamie Elliott: Beverly has also left the call; I know that for sure she's with the Health Information Privacy Office here at CDC, and also asked me to forward her information to all of you. She'd be very happy to help you out if you have questions.

Washington Participant: Okay, thanks.

Jamie Elliott: If there are no more questions, I'd like to thank you all, thanks to our speakers, particularly, for talking today on this topic and want to let you know we do have next week, a call that will be on cochlear implants and meningitis, and we will send out an announcement about that later on today. So, thank you for joining us.

Edited Transcript