REALTIME FILE

EHDI

A NEWBORN HEARING SCREENING TRAINING CURRICULUM FOR

MIDWIVES AND OUTPATIENT NEWBORN HEARING SCREENERS

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>> RANDI WINSTON-GERSON: Hi, everybody. I'm Randi Winston-Gerson, and I'm really happy to be here. The most fun thing I know how to do is work on this project and talk about this project and interact with this project. It's definitely a joy to be here, and really appreciate it. I appreciate all of you coming. I just would like to see, before we get started, a show of hands, how many people have actually seen the curriculum, the Newborn Screening Hearing training curriculum or are familiar with the content in detail? A handful. How about EHDI coordinators, how many EHDI coordinators are here today? Okay. Nice. Okay. Great.

So I'm going to let you know why this project was developed. For some of you familiar with the content, there will be a little bit of repetition, but I do want to share some of it with you so that everybody gets a little bit familiar with it before we go on to the new curriculum. But just a little bit of background on myself, I was part of the Arizona EHDI team since its inception. I was the consulting audiologist that went around to all of the hospitals. I did that for about 17 years, and my goal was to try to keep up with training and making sure that everyone was competent on equipment and knew what protocols to use, and it wasn't just about telling them what they needed to know. It was about training them on how to actually do it. And I grew up with this project, actually, by going out there and doing this, and learning what worked and didn't work in various hospital settings.

And after a very short period of time I came to the realization that there would be no way I could keep up in keeping everybody trained. I would get a phone call, day after day. There's somebody new on our unit. Can you come train them? And this was all over the state, 48 hospitals. So I realized that it wasn't really going to work in this way and I had to use a different approach. And I tried to use a train-the-trainer model which never worked because the information just gets diluted from one person to the next, so it was important to develop something to take a standardized message so that everyone was trained with the same information using the exact same material and there wasn't this just sort of telephone-tag game that was always being played.

So that's how this project started in 2006. And we've been at it ever since, and it's been -- it's been wonderful. So today, what I'd like to do is just show you for a moment our financial disclosure regarding this project. And Ginger, I hope I am representing Illinois correctly here, because I know in the past it hasn't been, but you'll straighten me out if it's not the right wording. But we're involved with the Maternal Child Health Bureau and the Illinois Department of Public Health as well. No equipment manufacturer is endorsed here as well.

I have to give a shout-out to the people by my side from the very beginning, some more than others, but just to say that we have shared such a strong vision and a deep passion for this, and for that, I am truly, truly grateful. And privileged. So I'm going to follow along with my notes, because I sort of get sidetracked on things that I want to say and forget other things.

So here, this slide really is supposed to be a visual for all the reasons why we developed this curriculum, and this is a fact, is that there is so much turnover in hospitals and nurse managers or an OB director is not competent enough to be able to train her staff one after the other on how to do this correctly. So there's a lack of standardized training tools, which if the people aren't trained how to do something the right way, they don't feel confident. They don't feel empowered in their role. So if that's the case, they're not going to do things correctly, which is going to have an impact on high-refer rates and poor screening practices and inadequate communication with parents. That's the biggest deal for me in this whole thing is making sure that babies and families get the best possible services and the best possible outcomes, and this is where it all starts -- with screening in the hospital.

And so as a result of poor communication, there's so much parent anxiety. I have a daughter who is in early labor right now as we speak. It's my first. So I've been in the hospital already with her, because she thought she was going to have a baby. So I sat next to her and I watched the nurses and I listened to people coming in and out of the room, and whoa, is that impactful, realizing how much impact those people that come into that room have on that mother and how they talk to her and how they address her and how she feels about being there. It's just a lot. So a lot of this speaks to that, especially in our communication piece of the curriculum which we'll get to.

But that parent anxiety has an effect on follow-up and how they perceive newborn screening and the importance of it. And things fell off of this slide. I couldn't get enough on here in terms of how negative it is without having the proper screening tools. To decrease the bottom one is to decrease community confidence, which is a big thing in programs that don't do things really the most competent way.

This is the current version that's online right now which I had up for a moment and I took down, but I'm going to show it to you. And what's so great -- I'm going to show you one section so you can get a feel of what the curriculum is and how it works and what it's about and how people are actually going through it. But this is -- these are all the highlights of it, and adult learning activities have been really helpful for people in learning, they're self-checks, all are based on the 2017 JCIH which will be updated soon. We are collecting data that takes this curriculum, so they log into a Moodle course, on the NCHAM website, allows you to have a login and a password, you take a pretest, a pre-self-assessment, and it's about how you feel about this, your knowledge about this, knowledge and attitudes. Then they take the course, then after the course is completed, there's a post test and a post-self-assessment. So we've been able to look at all the positive things, which is, the data has been fabulous in terms of improvements, and knowledge and improvements and self-confidence. And I won't get into that a lot. I presented on that at other conferences, but I'm not going to do that today, just to give you an overview of how great it's been.

There's also a certificate of completion from NCHAM. Anybody who completes with 80% or greater gets a certificate of completion. A lot of the hospitals and the outsourcing companies all over the country are requiring that people take the curriculum and that they actually present a certificate of completion which goes into their employee record. And that says that they are competent in conducting newborn hearing screening. They have the knowledge needed. So it's been great. We've added CEUs for nurses and audiologists, and there will be more to come.

So now I'm going to show you a few of the highlights from the curriculum, and hopefully I won't have -- I always say a little prayer before I walk in about technical glitches, because it seems like every single time there's technical glitches, but what are you gonna do? Just going to do my best.

So what I'm going to do is show you the table of contents so you can see the detail that's in this curriculum. It's about two hours long. And everything in it, I believe, is not nice to know, it's need to know. Every single part of it is important, and it shows that this is a complex program that has so many different elements to it that create this whole newborn hearing screening process. So that's what it is. It's a process.

The beginning, the very first module, which is, what is screening, is the most powerful one, in my opinion. Well, I'll say that about every one, and you'll say, well, okay, but it is so powerful. The screener, he or she is taken in and they are really shown why newborn hearing screen is important, what the impact is on the family. What screening is. It's not passing every baby, but it's separating those from the ones that should pass from the ones that shouldn't pass. It's all about the impact, the importance of early language development and communication skills. And so it's pretty powerful. And we find that if we show this very first module that it can be beneficial for support staff. It can be beneficial at the EHDI level for anybody working at a newborn hearing screening program. It can be beneficial for doctors. Any stakeholder can watch this and say, oh, my gosh, I get it. This is why we're doing this.

So that's the first one. I'm going to show you one module. Let me go through and then I'll show you the module I want to show you. But the second module is preparing to screen. Preparing to screen is all about getting that baby ready to screen. Telling the parent what they need to know about the newborn hearing screen, actually telling them that it's going to happen to their baby and what it's going to be like. Talking about the privacy of the baby. Talking about infection control procedures, all the things they need to know before they actually start the screening. What to say to parents, if the parents should refuse, trying to -- not change their mind, but let them be open, try to get them to be open to why this is important, because they may not even realize it.

So from there we go into the actual screening, which is here. Let's see if I can do this without sound, because I would like to -- oh, good. We don't have it at this point. Which is great. Okay. So module 3 is all about conducting the OAE, and it tells them the part of the anatomy as it relates to the OAE screening, when to screen, when they should do the screening, after the baby is born, when to really get the best outcome. And then it takes the screener through the screening steps. And as you can see, there's actually a close-up of conducting the screening. So the screener can actually see how to put a probe into a baby's ear, how to position themselves and the baby's head so that the probe stays in the head. We're talking about very fine details, and all of this is included in this curriculum. So even though they may not have a hands-on training that's all that great, they're going to get a lot from this.

They're also going to learn about all the possible things that could happen and all kinds of troubleshooting things that they can apply to issues that may come up. There's self-checks throughout every single module that allows them to check their knowledge as they go through it.

The same goes for automated ABR. We have anatomy. It's really the same material that's in the OAE, only as it relates to ABR screening. And the way that it's set up is there's an audiologist who is teaching a new screener, and it takes you through the story line of that audiologist training a new screener, how to actually do newborn hearing screen. As you can see, again, it's pretty much set up the same way.

Communication with parents and providers. This is all about language and culture, making sure that the parent you're talking to understands what you're saying and to, if not, get an interpreter if you have any concerns about it and find out in your hospital how to get those services if you need them. How to talk to parents. How to be sensitive to parents' feelings. And then how to actually -- there's how to actually tell them results. There's a script for every possible outcome. There's a script for passing, not passing, inconclusive. If the baby was screened and they didn't pass but they're going to get screened five hours later, what to say to them so they don't get scared that their child has a hearing problem at that point, or at any point. So it's very, very -- we hope -- parent friendly.

I think, Janet, you're in here, and you've done support for the parents also, and we'll be calling on you for the next phase, but that's the goal, to be parent friendly.

I want to show you one cool thing, in the scripts themselves -- let me see if I can -- so we have a script for not passing, and not passing babies at high risk, same with passing and not passing -- or not passing babies who are high risk, but the ones that actually pass that have a high risk, what to say to the parent so that they know that there's follow-up that's necessary after the screening process. But after this is all completed, there's a place to download a PDF right there on the spot so you can have it in your hand. So that's really nice.

The one I'm going to show you a completing the screening process. Let's see if I can get the sound.

>> The screener --

>> RANDI WINSTON-GERSON: Do it again? Thank you.

>> And the importance of the role of the screener in the EHDI process. Now, back to Jordan. As Beth instructs her on how to complete the screening process.

>> RANDI WINSTON-GERSON: Okay. So it allows --

>> It's time now to talk about completing the screening and your role in documentation and recordkeeping. I like recordkeeping and details. Then this will come easy for you. Documentation starts when you enter the baby's information into the screening equipment or the tracking program. Documenting results accurately helps to ensure babies with hearing loss get the help they need after they leave the hospital. Remember, good recordkeeping equals good data. Documentation is critical for follow-up, program quality, and legal reasons too. The hospital has specific guidelines for documenting screening results.

All hospitals require to send data to the state EHDI program. Do you remember what EHDI stands for? That one is easy. Early Hearing Detection & Intervention, because your hospital is part of a larger state and national EHDI program. The results you enter into the screening equipment or tracking equipment are sent to the state follow-up program. They used to track babies who didn't pass and needed follow-up and intervention services.

Now that you see how hearing screening fits into the bigger picture, let's talk about wrapping up your screening responsibilities at your hospital. Hearing screening is considered incomplete if the entire screening process isn't complete before the baby's discharge.

>> What do you mean by entire process?

>> The process includes making sure that complete screens are completed, that the family and the healthcare providers are given the results, that you schedule follow-up outpatient appointments with family and clearly communicate what comes next and make sure the documentation is complete. If you have any questions about how this is done at your hospital, check the hospital protocol.

>> That's a lot to remember!

>> Trust me, you'll do fine.

When you don't complete a follow-up due to discharge --

>> That's exactly right. That's when it's critical for you as a screener to screen all babies prior to discharge.

>> What are some reasons babies are missed?

>> For one, babies who are transferred to other hospitals get missed.

>> Why is a baby transferred to another hospital?

>> If a baby is born with a condition that requires more care than a hospital can provide, they're transferred to a hospital with the NICU. We'll discuss that in a later section.

>> Why would a transferred baby be missed?

>> Babies who are transferred in from other hospitals may not be immediately known to the hearing screening program, so it's important to identify these babies in the hospital. Ask the manager for the procedure in your hospital.

>> Wouldn't babies transferred already have had a hearing screening at their birth hospital?

>> Not always. The most common procedure is when a baby is transferred, the receiving hospital provides the hearing screen.

>> Any other reasons screening may be missed?

>> Another reason is due to early discharges. Some parents are just anxious to go home and want to leave early, and their baby may not have had a screening.

>> What can I do to avoid that from happening?

>> The best way is to check with the baby's nurse to find out when they're expected to go home. It's always a good idea to coordinate your schedules to screen the babies going home early first so you don't run the risk of missing them. If you're aware of a missed baby, know your hospital's protocol. It may require you to notify the attending physician or the medical home provider in a number of ways, including documenting the missed screening in the baby's chart, providing a printed report, verbally recording results, and/or sending a faxed report to their office and the state EHDI program.

>> Menu. Transcript. Module one. What is screening?

>> What is screening loss to follow-up provide?

>> Module 2, introduction.

>> In terms of family -- hospital, parent notification.

>> Frequently asked questions. What to say to parents. What to say to parents if they refuse. Accurate personal information. Protect privacy. Quiet environment. Infection control. Special handling. Inspection of the ear. Inspection video. For the best screening. Screening methods. Self-check to -- self-check 2 to 3. Self-check 2 to 4. Self-check 2 to 5. Self-check 2 to 6. Module 2 activity. Module 2 summary. Module 3. Screening infants. Module 4. Automated or abridged screening infants. Module 5. Communicating with parents and providers. Module 6. Completing the screening process. Module 6 introduction. Documentation and recordkeeping. Use of screening data. Completing the screening process.

>> RANDI WINSTON-GERSON: Here we go. I'm going to try one more.

So that's the course. I did not talk about -- talked about completing the screening process. Risk factors is based on the 2007 risk indicators. Recommendations for follow-up and how to really screen babies that have risk factors is what module 6 is, and module 7 is all about outpatient screening, which will lead us into our next curriculum, which I'm going to talk about.

So first, I want to just, for a moment, we put a recertification test on the curriculum as well, so anybody who has completed the curriculum and needs to be recertified, in six months, they can get on and they can take this very comprehensive 40-question test, and it really does cover all the real important and salient aspects of the curriculum. If they pass with a score of 80% or better, they get another certification of completion. They have two tries. And if they don't quite make it -- are we okay? Oh, okay.

If they don't make it, if they don't make the 80%, then they have to completely take the curriculum over again. So we're going to have two of those. We're going to start out with two of those tests so we can switch them out so people don't know all the answers. And then we're recommending that they retake the curriculum in three to five years or whatever their program requires.

So this is -- can you see all of it? Okay. This shows where the participants are congregated on a state-to-state level. And between 2015 and 2019, we've had almost 7500 people take the curriculum and get a certificate of completion. And you can see where it's really concentrated, in certain states -- Illinois, California, Texas, Arizona, and Utah it where at the state level they have really pushed the curriculum out to the hospitals. Some are requiring it and some are actually looking at data to make sure all of the hospitals are participating. So we are hoping -- and one of my goals is going to be to try and talk to the EHDI coordinators and see how I can help them in expanding the curriculum statewide to all the hospitals. Because in my opinion, there's really nothing to lose by doing that. It's a free resource. It's a wonderful resource. And they don't have any other resources. Our equipment manufacturers just don't have the training that's necessary at this level for screeners.

So anyway, I did get off on a tangent there, but just to let you know, this is what's happening, and we're seeing a lot of people taking it on an international level. Different countries are using it as well.

Here is just the progression of participation from 2015 to 2018, end of 2018. So we're really seeing a steady increase in participation as well.

So I put these up here, and I wish I could show them to you so that you could see them a little better, but we -- I collect comments from all of the people who take it, and most people make a comment. And I just took a few of them that I thought were really cool. These are the screeners that are taking it, and this is what they're saying after their experience taking it. There are a few negative ones, but really only a few, in all of these great comments. And the few are, oh, this is too long, why does it have to be so long, that kind of thing. But it does have to be this long. I think it could be longer. There's just a lot of information. So I don't get rattled by it. But I think the positive things are very, very cool. I like this one. I really enjoyed the training. It was informative and helpful. The only thing I didn't like, of course, was the reality of having to let the parents know that their babies didn't pass the screen but the good thing is, there's so much help and support for families of babies with hearing loss. I love that they walked away with that message. That's important to me. So I liked all of these comments.

So now let's talk about the outpatient newborn hearing screening module. So in our process of going out and training and working with state EHDI programs, we are seeing now a lot more midwives are getting trained, and they're using them in a lot of cases, using the current curriculum in a lot of cases, but we've had a lot of requests for outpatient birthing centers and midwifery programs to have a program that's more user friendly for that constituency and population.

So we started out on our process of developing a midwife curriculum, and very quickly, it dawned on me that there are other providers out there that are basically doing the same thing as a midwife. It's an out-of-hospital screening. It's an outpatient screening. Yes, the midwife is different, but I figured we could catch not only the midwife population but cast a net to all the other outpatient providers who are doing newborn, newborn only, hearing screening, whether it's midwife or Early Head Start program that takes in a six-week baby who hasn't had a screening, has no idea how to get a screening, or maybe they didn't get a rescreening, and give them the tools they need as well. So we're going to target this for that midwife and outpatient population.

I throw this slide up here again, the exact same reasons why we developed the first one is why we're doing this one. Same exact reasons. I want to give a special thanks to Karen Ditty who is here in the front row, and Stacy Jordan with the Vermont EHDI program who works very closely with me on developing curriculum, and to Patricia. I don't think she's here. But this is the first process. The next step is to send this content out to experts, subject matter experts in each of these areas to make sure the content is, you know, how it should be, the best that it can be.

So what do we call this? That's our problem. Do we call it the newborn screening training curriculum or the midwife newborn screening training curriculum, should it be nonhospital, out of hospital? It's a little bit complicated. Newborn screening hearing training curriculum for midwives and outpatient births. It's a handful. It's a mouthful. Whatever. I'm open for ideas, and if you have any, I'd love to hear what your ideas are. I don't want it to sound that, oh, because it's not in a hospital, it's not a good service, or compromised in any way. I just wanted to be -- I want it to be not too wordy, but -- I don't know. We haven't figured it out yet. We're working on that. But any thoughts, I would love to hear. Yay. Somebody raised their hand. And by the way, I would love to hear from anybody at any point. Thank you.

>> AUDIENCE MEMBER: All right. I'm an audiologist consultant in Oregon, and I work with all the very many midwives in our state, because we're one of the top five home birth state and their preferred terminology is community birth, so I don't know if community screening would capture all those?

>> RANDI WINSTON-GERSON: Yes. Any other thoughts? I love that, though. Really, that's good, because we're talking about county departments, pediatricians, family -- you know, family medicine doctors, all kinds of community health programs. So many are doing newborn hearing screenings. Thank you.

So it all looks the same here, visually, but it's not. It's different. The way that it's going to be is similar in the design -- oh, there's a question?

>> AUDIENCE MEMBER: I was just going to say that you can just call it what it is, just nonhospital screens, because everything is out of the hospitals.

>> RANDI WINSTON-GERSON: Yes. Thank you. So -- so the content appears to be similar, but there are some very, very big differences. It's a lot shorter. It will be a lot shorter. It's not necessary to go through a lot of the hospital things that we have currently. One of the biggest differences that I'm going to show you is the best practice recommendations, which is now a new section, that we didn't have in the last one. And in section 6, which is communication with parents, we are splitting it into two tracks. One will be for screeners, and one will be for medical providers, because it's very, very different what a medical provider would say to parents than what a screener would say to parents. So we're going to provide at a very high level, detailed scripts that a medical provider could use. Also, section 7, the risk indicators, most out-of-hospital screeners don't need a lot of detail on risk indicators. They need some general guidelines and they really need to know what's important, like asking every parent if they have a family member with congenital hearing loss, those will be in the curriculum, but not a lot of things they'll never come into contact with. So the risk indicator section will be a more serious section geared toward the medical provider.

So, again, section 1 is the same. Exactly. We didn't see any big changes that were needed. The best practice recommendations and considerations is very meaty, lots of meat and potatoes in this one, because it's got all the information they really need in one -- in terms of best practices and protocols in one fell swoop. So when to screen, how old the baby should be, when to conduct a rescreen, and we're talking about the one, getting all the screenings done by one month of age, preferably by two weeks of age, when to rescreen after the initial screen. You have to remember that most of these are going to be rescreened. They're going to be screened in the hospital or by a midwife. There's lots of recommendations for midwives screening. What are the intervals? It's different intervals than in the hospitals, following midwife guidelines as well. So we want to integrate best practices there as well.

What's the optimal age, and if they're going to an outpatient setting, we need them to be checking electronic health records to see what the results are, not just a parent report, or some sort of documented thing. These are things they need to be aware of if they're going to screen a baby as a physician or midwife. And also, one year may have passed or before, they have to screen both ears in order for it to be considered passed.

Babies that should not be rescreened. They shouldn't be rescreened if they've been in the NICU for any period of time. They should be going to an audiologist instead of getting a screening. Babies, if they had an ABR and didn't pass, they shouldn't have an OAE as a follow-up screen. There are some other considerations with that, and it will be interesting to see when I send this out for review what people's comments are on that.

Special consideration. Malformations of the ear. Do we want to screen those ears? Do we want an outpatient screener or a midwife to screen a baby that has a malformation? So it's giving guidelines around that. Considerations when babies are older than one month of age come in. Not all equipment is meant to screen babies older than one month of age. If you're using OAE equipment, you need a different probe tip, a different size, or you'll have problems. Whether they pass, whether they're referred, whether they're a baby with any kind of risk factor or whether they passed and were in the NICU and are showing up for a rescreen. We have all of those scripts that we're going to have embedded in this as well.

Documentation, the importance of it, reporting to the states, and all about the EHDI program is in here, and also, all of the NICU follow-up, making sure that an appointment for the next step is scheduled, if possible, and contacting the medical home and making sure that the family has a copy of the results. All of the best practices will be in this one section.

Does anybody have any questions at this point? Yeah. I kind of had a feeling.

>> AUDIENCE MEMBER: Do you provide links to state-by-state guidelines?

>> RANDI WINSTON-GERSON: Yes. And this is in the current curriculum as well. There's a resource section, which is full of lots of different websites and materials and resources. And included in that is a link to the NCHAM state map with all of the state-specific resources. I saw another hand. Hi.

>> AUDIENCE MEMBER: Hi. My question is regarding -- I guess the risk factors that you were talking about, and if -- I know, you know, Illinois, we have the law of, if a baby fails two hearing screenings, then the parents get an option for testing for congenital CMV, and if this is a part of the training for the screeners and who would handle those questions.

>> RANDI WINSTON-GERSON: Great question. We don't have it currently in the curriculum.

>> AUDIENCE MEMBER: Okay. Is there a reason for that?

>> RANDI WINSTON-GERSON: The reason is -- yeah. It's.

>> MAN: (Away from mic).

>> RANDI WINSTON-GERSON: And that's a good point, the ability to link. Would you like to see recommendations specific to the follow-up with CMV?

>> AUDIENCE MEMBER: Yeah, I think just because it is a public health concern and there's a lot of data that shows that it's the leading viral cause of hearing loss so this could be a part of the screener's basic knowledge of what this is and how to, you know, it can be a part of the parent conversation and what that is. Obviously, legislation requires it in Illinois for the parents to get information, but the screeners having a basic knowledge of that as well as, you know, how they're going to be directed, that conversation with medical providers and allowing the parents to have that additional test while they're still in the hospital is crucial for, obviously, follow-up and making sure that the baby is, you know, being tracked for the progressive loss or anything else that was soliloquy from that.

>> RANDI WINSTON-GERSON: We don't have that from an outpatient level, but ensuring that babies get the follow-up they need, even though they may not be working with that population of babies, it's still important to provide that information. So the answer is yes. We will definitely include it. I agree. Any other questions? At this point?

>> AUDIENCE MEMBER: I have a question. What do you do when you get comments from screeners whose state protocols may vary differently from what you're promoting?

>> RANDI WINSTON-GERSON: I don't get questions usually, but I always will defer to the state protocol because that's what should be followed. But throughout the curriculum, it is suggested at the end of almost every slide to follow your hospital protocol, and let's just hope that their hospital protocol is following the state guidelines. But always. Because there are some differences, especially when we're talking about whether to screen a baby with one ear that may have a malformation and another that may be normal.

>> AUDIENCE MEMBER: And the outpatient for the medical portion where you're talking to parents, do you have a sample script to show us?

>> RANDI WINSTON-GERSON: I do. That's what I was asking them. I did ask them to load the scripts on the computer for me, and they didn't. So I brought them with me. So I can read one to you.

>> AUDIENCE MEMBER: That is definitely of interest. And where did you -- did you get medical providers' input on developing these scripts?

>> RANDI WINSTON-GERSON: Yeah. So -- yes. I was asked to do this by the AAP several years ago, Karl asked me to develop these scripts and I did and they were disseminated amongst the AAP. I got some feedback, but I just -- sort of is out there as a resource for pediatricians. At this point before it goes into this curriculum, it would be really reviewed properly. It was just -- I was just asked to do it, and so they're out there. But I think they're good, and I think they can use some work, but I think in general, yes. They will be reviewed.

Right. Karen is saying that everything here is used as a guideline. It's not, you know, exactly what people may do, but these are a place to start, a good place to start. So -- I'm getting a repeated call from my sister. This makes me really, really nervous. Yeah. And I'm saying this because my daughter could be going into labor at this moment, and here I am. Yeah, I would love it if -- (Applause).

>> RANDI WINSTON-GERSON: Freaky. This never happens, but it's happened three times since I've been standing here. She's in Arizona. That's why it came, because -- I'm right across the street from a thousand airplanes. I can get home well before you have this baby. It's not going to fall out of you. We hope not. It's her first.

Anyway, these are the scripts. So getting ready to screen, that's section 3. But I'm going to skip over this. Four and five, OAEs and ABR are very, very similar to what's in the current curriculum, only everything has been adapted for outpatient screening because it's different.

So now, we talk about the outpatient screener scripts. These are what we currently have. If anybody sees anything that's missing or thinks needs to be added to this, I would love to have your feedback on that. Then we have the medical provider scripts.

The goal of the medical provider scripts are for there to be scenarios for every single possible outcome that they're going to have when interacting with a baby. So we want detailed scenarios with lots of key messages and so they can effectively communicate outcomes and address next steps with parents. So right now, this is a list of what we have. I've got a couple of others that maybe brewing, but this is what we have so far.

I like the third one because I think that often parents show up at the doctor's office. There's fluid in the baby's ears. There's some sort of message that they should wait for the fluid to dissipate before they get either further testing or diagnostic testing and a lot of this is really -- straighten out this misconception in these scenarios.

Failed the inpatient and outpatient screen. In the medical provider's office, because now we have medical providers providing the screen. So these are what we have so far. And I'm happy to read -- I was going to show them to you, but they're not loaded on the computer, so I can just read what an example of what I have.

So really -- I'm sorry that I don't have them on here because we have basic tenets that talk about the 1-3-6 and we talk about the importance of not delaying with regard to it being a developmental emergency. We talk about the role of the pediatric audiologist and not assuming that the ENT has really good pediatric audiology practices. And to really diagnose a newborn baby with hearing loss. And that that assumption is often made. But this can, as I said earlier, delay the process.

So let's see. Pick one. Failed inpatient screen. While in the hospital, your baby received a newborn screening and did not pass. We can't know if your baby's hearing is normal until further testing is complete. It's critical that we find out if sound is getting to your baby's brain in order for speech and language development to occur. Development begins as soon as babies are born. If your baby has a hearing loss that goes undetected, he or she may be delayed in their development and may never catch up with children their own ages.

I ran that by a couple of new moms and I think -- ten minutes? That sounds a little strong, but I'm on that line of wanting it to be strong, but not too strong to get them to do the follow-up they need.

Even a minimal hearing loss or hearing loss in one ear can prevent normal development of speech and language skills. If an appointment has been scheduled for an outpatient screening, please be sure to keep the appointment. The younger your baby is, the more likely he or she will sleep for the appointment. This can help the appointment go smoother. If you don't have an appointment scheduled, my office can assist you in scheduling one. And if at the appointment your baby does not pass the repeat screening, contact my office immediately so we can review the results and discuss next steps. If you have any questions or concerns, contact my office.

For every single scenario there's major bullet points on all kinds of things that can be said to address all of the possible things that need to be said to that parent.

I'm going to kind of go through these pretty quickly. Because I only have ten minutes left. And I want to take any questions that there still may be. So this is what happens when it's done. We're getting close. We're waiting for the new JCIH risk indicators to come out so we can update it. So we're at a standstill until it happens, and hopefully we'll see that soon.

Then we've got a little study that we're doing right now. With two states, Illinois and Minnesota. And Kiersten covers -- and Ginger Mullen are working on this, to implement the curriculum statewide and look at outcomes, really, at a systems level. So the goal is really to get every single hospital to take the curriculum, but it's going to go through the nurse manager who is going to implement the curriculum along with a hands-on checklist to see that every single person who is screening takes this course, and then we're going to try to understand what their concerns are, what their challenges are, what -- you know, in the process of implementing the curriculum, what are the things that we are going to see as improvements in outcomes as a result.

So I'm going the wrong way. So how is this for a new nurse manager who has to implement this, and what are their challenges and barriers? There will be data collected before and after so we can look at the before and after outcomes. And that's pretty exciting, and it's something we need to do because we're going to look at refer rates, we're going to look at loss to follow-up, both before and after we implement this. So something we've needed to do for a while.

These are just a few of the steps we're going to go through to do this, and I'm breezing through because I want to take any other questions. Why should states implement this? And I think I've spoken to that already throughout this. But I really would like to see at the state level this become -- this be used a lot more than it is. And I think every hospital should take it. Unless a state has their own training that they've implemented, something standardized in their own state, which I think is just great. But if they don't, at least this is something that can help screeners gain the knowledge they need to do a good job in their roles as screeners.

Any other questions or any questions or comments at all? I appreciate the ones so far, but I'd like to take a few minutes for those. Yes. Do you have a microphone?

>> AUDIENCE MEMBER: Thank you. So I'm in agreement with you. I tend to err on the side of caution when counseling for rescreening and I'm hooked on that one bit of feedback from that one trainer who loved the trainer but was anxious about giving that news to parents that the screening was failed. At the Virginia EHDI meetings we often have families come in and sort of give their story on the path to diagnosis and so on.

And a common thread there is that they receive the newborn hearing screen, and the technician or student, for whatever reason, the news and the said for whatever reason, it's in the ear, it's fluid in the ear. Failed screenings happen. It's nothing to really worry about. So may be valuable to teach at some point in the training, be aware of the common reasons why a baby may not pass a screening and may end up otherwise having normal hearing but not convey that and necessarily minimize that risk in the parents' minds.

>> RANDI WINSTON-GERSON: Totally, totally agree, and it's in there, and the scripts for every single scenario for the screener is very straightforward, and we talk about that, the importance of not diluting or minimizing the message. Absolutely. Thank you.

>> AUDIENCE MEMBER: I agree with what our last comment said. As an audiologist trained, they come in, no, no, it's fluid, that's what the nurse said. Well, it's not just fluid. So I think that's a really important comment to know that minimizing it and downplay it to calm down your mom at the initial screen does no good. I agree with his comment.

>> RANDI WINSTON-GERSON: I know, and it's using straightforward language, not give them reasons why they may not have passed but say, what's important is that your baby gets follow-up.

>> AUDIENCE MEMBER: And I started the first newborn screening program in Colorado in 1992. It's been an issue then and it still is. Some things never go away. Hey, Randi, when are you anticipating this will go through the final phase?

>> RANDI WINSTON-GERSON: We're done with the content in terms of anything that doesn't need to be updated by the JCIH new guidelines, and then we have the CMV request that will go in as well. We have to send it out for review, and that process will take about a month. So I would guess in six months, eight months, like that.

>> AUDIENCE MEMBER: I think Vicki's comment that we still see that as an issue, I think that's something, we can only do so much as a curriculum, and if they don't read the scripts and whoever their manager is doesn't make sure they do that, we're locked out of that world. We're not there with the baby. This is the best we can do short of going in and walking everybody through a training. What is important is that whoever manages it at that hospital, whether it's an outsourcing group or a nursing manager or whoever it is, they need to be aware that they follow and they shadow those screeners until they feel comfortable that they're saying the right thing until this doesn't happen -- the parents said, well, they said not to worry, there's a bunch of gunk in there.

>> RANDI WINSTON-GERSON: But nurse managers, OB directors, the people implementing protocol watch this because throughout this whole curriculum are the recommendations, the best practices. But the screener is only -- a lot of times just the screener. They don't have the ability to change protocol, but the OB directors and nurse managers do. So it would be great if we could have a new program where directors of hospital programs have to watch this. We should probably do this with a study. It's important. Thank you. Yes.

>> AUDIENCE MEMBER: And this training curriculum is mandatory in this state, and trainers do this all the time. We come across this issue of what they say and what they don't say. Have you ever considered putting a live parent who did not buy into the system because of what they were told on these videos?

>> RANDI WINSTON-GERSON: There's one. It's powerful.

>> AUDIENCE MEMBER: It is, and my screener is like -- they do this because we make it mandatory annually for them to do this and at this point they're like breezing through. But when I brought a real-life parent to do a training, because we do competencies as well, it made that much of a difference when they hear it from a parent who didn't buy in because of what they were told at a screening.

>> RANDI WINSTON-GERSON: I agree. The one parent who talks about the importance of a screener's role in communicating with parents and what they say and what the facial expression is, all those things that are so critical makes a difference. I agree with you. Very powerful.

>> AUDIENCE MEMBER: Hi. I'm an EHDI coordinator for the state of Georgia, and one of the things that we do -- we follow up with the parents. So after they're tested in the hospital, we immediately call them. And so basically we're trained to speak to them and let them know the next steps, and we're going to be with them until the testing is completed or they are diagnosed with hearing loss and we refer them to the resources.

>> RANDI WINSTON-GERSON: Awesome. One more question?

>> AUDIENCE MEMBER: Hi, more of just a comment on the second-to-last comment, that family, it's smart to have those family stories of parents who got bad information or whatever or incomplete information from the screeners, you know, and in -- I just wanted to put out as a resource, we see families who are often families who passed the newborn screenings that later on have progressive hearing loss and don't necessarily know about the follow-up with the screenings. We are a loud group of families that are willing in every state to come and be a part of this family story that might have some impact, because I know that my son was born with perfect hearing and, you know, has since lost it, profound loss on the left side. So there is a big group of us willing to help in any way you can if you need families.

>> RANDI WINSTON-GERSON: Do you have my email address?

>> AUDIENCE MEMBER: Yes.

>> RANDI WINSTON-GERSON: I would like to know who anybody is who would like to be a part of this.

>> AUDIENCE MEMBER: We have a parent registry now. Is that going through EHDI? The national CMV.

>> RANDI WINSTON-GERSON: Thank you. Thank you, everybody.

(End of session at 12:17 p.m. CT)