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WHY DOES IT TAKE SO LONG TO COMPLETE THE AUDIOLOGIC PROCESS?

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(Writer standing by.)

>> Okay, so, we'll start the webinar in about 5 more minutes. Today, we're going to be listening to Dr. Choojitarom on why does it take so long to complete an audiological process. So, again, we'll be beginning the webinar in about 5 minutes, and if you would, in the meantime, rate the quality of audio. You've heard of kind of talking back and forth a little bit about being able to hear one another, so you should be able to hear us okay, I hope, so if you'd please mark if you can hear us or not, that would be great. Okay, it looks like most people either have good or excellent audio quality, which is exactly what we want to see. All right, we're going to go ahead and get started. This is Allison Ward at the NCHAM headquarters in Logan, Utah where it's raining and thundering this morning, so hopefully, that doesn't interfere with the audio. We're happy you're all

joining us this afternoon Today, we're going to be listening to Dr. Choojitarom talk to us about why does it take so long to complete an audiological process. Dr. Choojitarom is the regional network liaison for District 7, as well as he serves on the Louisiana State EHDI Advisory Council, and he's done that for the past five years and been chair of the council for the past two years. I just want to let everyone know that this webinar will be recorded, as you just heard, and will be posted up on the infanthearing.org website within a week. Again, we appreciate your attendance. We'll be doing questions and answers after the presentation, and, um, and just through a type-in format, you'll see a field at the end of the presentation where you can type in questions, and then Dr. Choojitarom will answer one question at a time. All right, without further ado, I'll turn the time off to Dr. Choojitarom and we'll go from there. Thank you.

>> All right. Hi, everybody. Thank you for attending this webinar. The subject is very, very interesting. As she said, and pronounced my name very well, I might add, I'm Thiravat Choojitarom. Before I begin, of course, I always like to say that I have no, you know, financial investment in any of these things, nor will I be discussing any off-label uses or anything like that. Um, so, before I kind of get into it, a great deal of credit goes to Ian Ng, who's a masters of public health student, and Dr. Tri Tran. They are the real workers

behind this information and this data that I have the pleasure of presenting to you guys today. Okay, so, let's go ahead and get started. Our EHDI missions and goals, everybody is familiar with this. I'm basically preaching to the choir here, but we're going to focus our attention really on the goals of that screening for hearing loss before hospital discharge or before 1 month of age and the complete audiologic diagnosis before 3 months of age. However, I would like to sort of clarify a couple of terms, because the way that we look at some of this is a little bit different than how the CDC looks at some of this information, and it can be a little confusing.

So, loss to follow-up, you guys know about, as well as loss to documentation. There's this idea of in process, and CDC says that in process is the baby had failed a newborn hearing screening, had one follow-up and is still waiting for a confirmed diagnosis of some kind. CDC also says that that's only a six-month period. After that, I'm pretty sure that they just classify them as loss to follow-up. We, in this study, did not do it that way, we did not put a time limit on it. Now furthermore, CDC also says that if a baby fails their hearing screening and you don't have a disposition for that baby one way or another, they simply call it no documented hearing diagnosis. So, the figures, of course, look pretty awful because they include loss to follow-up, loss to documentation, and that in process thing that I mentioned

before. So, the next slide here is kind of my graphical representation of what we're talking about. You know, we all feel that there is an influence of demographic factors in everything that we do. Further to the left, I believe they're more sort of medical influences or medical factors that affect our hearing screenings. As we go further to the right, it becomes more a majority of issues with our EHDI systems.

>> Dr. Choojitarom, I apologize for interrupting you. I know we have several people joining us by phone today, and it's sometimes a little challenging to selectively mute, so if you are joining us by phone, please make sure that your phone is on mute so we don't get any feedback from your speakers or hear you shuffling around at all. Sorry about that. Go ahead and continue.

>> Okay, so, specifically, we wanted to look at those patients who did not pass a newborn hearing screening, were not loss to follow-up, loss to documentation, and in this sort of twilight zone, which we call incomplete audiologic diagnosis. Now, we kind of suspect that there's, you know, several factors involved with this, but looking at the data, sort of three things sort of stood out for us, and that is the age of the newborn hearing screening, the length of time between that first newborn hearing screening and the first follow-up, and lastly, the total number of follow-ups, but we also wanted to take a look at the sort of demographics of the

situation too and see if that had an influence on this incomplete audiologic diagnosis. These are our study parameters. I'd, again, like to point out a great deal of work that was done by our public health team and Dr. Tran to get this information together. Our study criteria, we started in 2011 through 2013, and again, it had discharge before leaving the hospital, failed that newborn hearing screening, had at least one follow-up service, and we excluded loss to follow-up, loss to documentation, and if the infant expired. This, I'm not going to go through this whole breakdown of our population demographics, but I did want to include it in case you were interested in looking at it on your own after the webinar was over. Okay, so, this is how we broke down our sample size from the over 180,000 newborns screened.

We had a prefer rate of about 5.4 percent, almost over 9800 failed. Of that, applying our study criteria, we had about, almost 7,000, about 71 percent fit our study criteria, and of that, 478 were considered incomplete audiologic diagnosis. It turns out to be a rate of about 6.9 percent average from 2011 to 2013. Interestingly, if you look at the loss to follow-up rate or the loss to documentation rate, it also was inside of the range of 11 to 14 percent during that equivalent time period. Okay, then we took the demographic data, and then we asked ourselves, did that have an influence on the percentage or the risk of incomplete audiologic

diagnosis, and this is kind of what we see. There is clearly an affect here with the incomplete audiologic diagnosis. Rural versus urban, number of previous live births at about 8 percent. Impact, yes. How significant? Not quite so sure. Particularly in comparison to our hypothesis, which is the age at the newborn screening. At less than 30 days, 6.1 percent. 30 days plus, it jumps to a rather striking 25.7 percent. Same thing for your total number of follow-ups. One follow-up is not that bad, two or more follow-ups, and you have almost 20 percent incomplete audiological diagnosis. So, a great deal more than those demographic factors.

So, let's kind of look at it based on odds ratios, or adjusted odds ratios, you know, compared to 30 days, greater than 30 days, for age of newborn screening, as well as time between the newborn hearing screening and the follow-up and the total number of visits, and we see that there's a huge difference, increase in the odds ratio of the risk of incomplete audiologic diagnosis if the age of newborn screening is greater than or equal to 30 days. Same thing for time between newborn hearing screening and follow-up, and more strikingly, if there's more than one follow-up, the risk of incomplete audiologic diagnosis goes up tremendously. It's quite striking, really. Okay, so, let's kind of compare the effects of the odds ratios for our demographics versus our hypothesis, and this is kind of to show you the relative impact

of both, and it's just quite clear that those three factors of our hypothesis had a much higher impact on the rate of incomplete audiological diagnosis. Now, this is not suggesting that demographics don't have an influence. We know there's an association with some of these risk factors, such as low birth weight, urban setting, poverty, etc., things like that, so we started asking ourselves, with respect to these demographic factors, particularly birth weight, is there another association? So, we did, we stratified the age of newborn screening by birth weight, and this is what we got. Notice, very low birth weight infants had a huge risk of incomplete audiologic diagnosis.

Okay, if you look at low birth weight or normal birth weight, their risk factors, not nearly as great, but again with our hypothesis, greater than 30 days for age of newborn screening increased the risk of incomplete audiologic diagnosis to almost 4 percent for low birth weight, not 4 percent, sorry, 4 times more for low birth weight, and 6 times more for normal birth weight. So, let's look at the other, the time between newborn hearing screening and first follow-up. Once again, very low birth weight infants had a huge risk, pretty much regardless of the hypothesis or not, whereas the other categories of low birth weight and normal birth weight seem to fit very well with our hypothesis. So, um, I just think it's such a striking change, some really very interesting

information to work with. Last, of course, total number of follow-ups, and once again, very low birth weight infants, very high risk, but I thought it was also very interesting that even for low birth weight and normal birth weight, more than two visits raises their risk of incomplete audiological diagnosis very significantly. Okay, so, sort of, you know, in conclusion, I would say that incomplete audiologic diagnosis remains a big problem in Louisiana, and of those factors, of course, late newborn hearing screening, long periods of time between screening and follow-up services, high number of follow-up services, and as we dug through the data, very low birth weight infants. So, this kind of brings us back to this little cartoon graph that I have here about the sort of hearing screening that we do.

One of the great strengths of the study, I think, are the data linkages between the mother's information and the newborn information. This is a great deal to do with, you know, Dr. Tran's hard work and his whole group, as well as our whole EHDI team in getting this data together. It's also very helpful that we have the EHDI IS system, which is a sort of online database system which really allows us to mine data really, really well. So, I believe you can use this data in a number of different ways. One, you could use it kind of as a method of directing intervention. If what you're doing as an intervention addresses one of these three factors, time to

first follow-up, time from first follow-up to the next follow-up, or the number of follow-ups, our model would predict sort of a high rate of success for those interventions, interventions that didn't address that. Say, for example, you're creating a minor system for patients, but you didn't really address the availability of appointments of services, you know, so, the actual time that it took to get that appointment didn't change, our model would kind of suggest that that would not be quite as successful. Um, but likewise, you can kind of look at this study and say it's a way of evaluating your population. If you look at our demographics, I think it looks fairly homogenous. I think it's reasonable population, probably similar to most populations with this urban suburban sort of setting, but I think it would be unfair to necessarily generalize it to other states and other populations, but I think if you did a similar analysis, you would find sort of these little surprising associations within your data, and again, you can utilize this to ask yourself, you know, where is it that we need to target our intervention.

So, one particular weakness, I think, with this study though is that we have association, but we really don't have causation. We need to look more closely at a number of different factors, especially the very low birth weight infants, as well as the causes of late follow-up, multiple follow-ups and prolonged follow-ups, because there can be

numerous reasons in the case of NICU or very low birth weight infants in terms of their medical diagnosis. I mean, generally speaking in the United States, pre-term birth is approximately 12 percent, and low birth weight is approximately 8 percent, it's about 11 percent in Louisiana, and NICU rate, admissions rate tend to be around 12 percent, and C-section rates tend to be about 30 percent. So, you know, reducing those pre-term births and low birth weights would definitely help, and this sort of takes the discussion a bit outside of what we normally look at in our EHDI systems. I would love to see more primary care emphasis, I would love to see more emphasis in the area of the medical home and access to care and things like that, but, you know, coming back to EHDI, even after discharge, there can be a number of factors that influence this; demographic factors, like I said, not just a geographic availability of services, but appointments, transportation, things like that. Finally, the audiological diagnosis is sort of a slice in time in a dynamic situation. So, we didn't contact the patients or the facilities to sort of get a disposition, so we don't really know how this sort of eventually turned out, and it could be, if the study times were different, we would have somewhat different results, but let's take a look at some more practical aspects here. Patient compliance, or non-compliance, as it were, although we didn't see a great deal of influence from the demographic factors, they did have an affect. Geography, age,

education, you know, perhaps they weren't impressed by the need for follow-up, or they simply forgot.

So, things that I think are still worth addressing, and of course, addressing resources and availability of resources, which I kind of mentioned a little bit earlier, and, um, in terms of service providers, making sure that the primary care providers are well-informed as to the importance of the timely diagnosis, as well as reporting to their state EHDI representative. Now, one issue that we had was the referral process. Patients would get seen by an audiologist or a PCP and get referred to another audiologist, but never show up, so we had a project where the audiologist that was referred to, in other words, the audiologist receiving the referral, was also told to expect the patient. So, you know, what happened was that the informed audiologist was told to expect this patient to show up, so by making sure that the referred service provider knew that the patient was coming, it created an opportunity to make contact with the patient in two different ways, and it also gave our EHDI team an opportunity to know where in the process the patient was. It also helped to emphasize the importance of, you know, completing the work-up that was started from the initial failed newborn hearing screening, and the issue was not placed on the back-burner and sort of forgotten about.

Now, with that PDSA, we can see that by targeting

interventions based on this data, it sort of allowed these PDSA cycles to target, this one particularly for audiologists, and reduce that sort of in process time by assuring that communication between service providers, decreasing that gulf of time from referral to service, and also, perhaps addressing, another thing that we could do is address the number of follow-ups by PCPs or by audiologists, you know, and that would also, by our hypothesis, decrease the incomplete audiologic diagnosis rate. There was, when I first gave this talk at the last EHDI meeting, national EHDI meeting, I was talking about it at our stakeholders meeting, and one of the parents sort of, you know, came and talked to me and said that, um, her child was diagnosed with hearing loss in the newborn hearing screening, had a follow-up appointment with the audiologist, and then had another follow-up with another audiologist, and another follow-up, for a total of eight follow-ups before she had a diagnosis. Now, I'm not sure if this is an indicator for a need for guidelines, I don't know if this is an indication that, um, more testing or training is necessary, and certainly, it's not an easy task, to do a hearing screening on one of these really small primis, or perhaps a child with multiple medical issues, but I think that's certainly an avenue that we can look at to help our in process/incomplete audiological diagnosis rate. Okay, um, I tend to talk fast, I apologize if I went a little fast. If any of you have any questions, I'll

be more than happy to answer them for you.

>> Okay, thank you, Dr. Choojitarom. I appreciate it. That was great information, and I'm sure our listeners have a lot of questions. So, over on the bottom left side of your screen, you'll see a Q & A box. Go ahead and type in your questions there, and then Dr. Choojitarom will answer them, and if we do end a little early today, I'm sure that is just fine. Okay, so, our first question has come in. How did you decide to focus on low birth weight as opposed to other risk factors?

>> Well, that, really, when we were looking through the data particularly, we started to see a lot of that information coming from hospitals and NICUs, and we had suspected that the medical factors had a great deal to do with, you know, what was going on with our in process problem there, so that seemed to be a good place to sort of easily stratify the demographics of the patient.

>> Okay, great. Another question, we've had issues with children in foster care receiving the follow-up screens that they need. Is that something you saw in your research at all?

>> No, we haven't, and that is, I think, one of the weaknesses of the study, is that we didn't really dig any deeper into the reasons for it, we just simply connected the mom to the child's hearing screening, and then we kind of took

it from there. So, you know, if there was a foster case, I honestly don't know what happened with that data. I'd have to ask Dr. Tran.

>> Thank you. The next question is what is the specific difference between loss to follow-up and loss to documentation?

>> Oh, okay. Your loss to follow-up is, um, so, they have the, they fail the newborn hearing screening, and, um, they never seem to, they have an appointment, and we don't have any results from them, we don't know where they've gone, we don't know what happened to them. Loss to documentation is that they had failed the newborn hearing screening, and we don't know if follow-up has occurred at all, they've sort of disappeared. They could have moved away, they could have simply refused, so we don't know what happened to them, we've kind of lost their paper trail, in that case.

>> Okay, great. The next question is where are screenings generally completed in Louisiana?

>> Generally speaking, it depends on the region. For example, in the Baton Rouge area, there are abundant audiologists that have their own sort of practice, or they're at the hospital. Like, Women's Hospital, we send a lot of our babies there for screenings, or I even send a lot of our kids there for screenings, but in other areas of Louisiana, that's kind of an issue. If you go to north Louisiana, there can be

maybe one audiologist at one of the hospital centers, and it takes an hour or two for the patient to get to that one audiologist. So, it sort of depends on where you are, you know.

>> Okay, great. There's just a comment in here, just in response to the lady that you mentioned that it took eight follow-up appointments with a diagnosis, there's just a comment in here, um, from a listener saying that multiple audiologists, in parenthesis -- who is a pediatric audiologist. Is that something that you're seeing in Louisiana? Where, you know, audiologists that are actually skilled with working with infants are identified in a specific way? Do you have a good way to decipher, you know, who says that they're a pediatric audiologist versus those who are really qualified to make a diagnostic evaluation on an infant?

>> That's a great question. I'm not really sure what the answer is, because I don't, um, I don't really know the audiologists well, but, maybe it's kind of an assumption of mine, but, you know, if you know you're doing a follow-up newborn screening, I would sort of hope that you'd have at least a fundamental knowledge about how to do a screening on a baby or a newborn. My concern would be that despite being adequately trained in, you know, infant audiology, that there may be very difficult cases, such as ex-preemies, or babies with certain medical or physical conditions which make that

testing more difficult. I don't really know, in this person's case, if there were any issues of that type, but, yeah, I can't speak to how the audiologists sort of, you know, advertise themselves out in the community.

>> Okay, great. Um, the next question is is there data on children whose parents have a confirmed hearing loss?

>> SPEAKER: Is there data on, you mean the parents of children with hearing loss?

>> Yeah, yeah. I don't know if you were able to look at that as a demographic factor.

>> Yeah, we didn't look at that, but generally speaking, that's sort of a known quality. We know that 90 percent of children who are born with hearing loss have normally hearing parents, and vice versa, so, you know, one of the things that we work on in our EHDI system generally is, you know, parent-to-parent communication. You know, we have someone who's diagnosed with hearing loss, we have a parent that's a guide by your side group or the hands and voices in Louisiana, that goes and talks to those parents, because most of the time, 90 percent of the time, you know, the child with hearing loss is born to hearing parents, and, so, they need to be sort of well-informed and educated as to their options and, you know, what they can do to help their child. So, yeah, for the most part, we know that about 90 percent.

>> Okay, great. The next question is have audiologists provided a reason for why there are so many referrals and follow-up appointments before a diagnosis is made?

>> Not officially. I would tell you that sort of unofficially, one reason has been you don't want to be the one to sort of tell them your child has a hearing loss, and that can be just a product of training and experience. Two, there's always, you know, kind of, it's subject to a bit of interpretation, so, you know, they're hesitant to make the diagnosis, and that's sort of the impression I got, talking to several audiologists and to the audiologists on our council.

>> Okay, great. The next question is actually kind of related. Um, what are your recommendations from this study in regard to ensuring audiology facilities are performing the appropriate and timely testing?

>> That's actually one of the objectives for our, you know, group here in Louisiana, our EHDI council, is sort of to reach out to audiologists and assure that they're, you know, properly trained and following the correct protocol when it comes to infant hearing re-screenings, as it were, or diagnostic testing, as it were, and, so, we're actually holding some educational conferences that invite, you know, audiologists, as well as, you know, interventionists and parents of children with hearing loss, and we'll have a sort of

educational session that talks about these issues. In terms of getting sort of deep down to the education of audiologists, one of the audiologists, we have an audiologist on our council, it's mandated that we have an audiologist with us, and you know, they're always working to make sure that they're, where they're learning audiology, that they're learning this, and it's not unusual that sometimes, the whole group of audiology students at our council meetings, you know, so, I think it's kind of this work in progress sort of thing. We can always be doing something more, but those are some of the steps that we've done to sort of make sure that the audiologists know what the process is.

>> Okay, great. The next question is does Louisiana EHDI plan to reallocate resources to no-compliance families based on the research?

>> Yes, definitely. That's the whole idea behind doing this, is to sort of re-trigger our interventions, you know, to target those three hypothesis. Like I showed you in that last slide, that was a PDSA that our outreach coordinator did. You know, again, looking to decrease the time between that first follow-up and the next follow-up, as well as hopefully decrease the number of follow-ups, and I think by targeting that, it decreases our incomplete audiologic diagnosis, and hopefully, generally speaking, will also decrease our loss to follow-up, loss to documentation rate,

but, you know, remember, this data looks really not at loss to follow-up, loss to documentation, it really looks to that somewhat smaller slice of the pie that we labeled incomplete audiologic diagnosis, but I think that if you apply this data specifically in that way, you are going to generally decrease your loss to follow-up and loss to documentation rate, or at least that's our hope.

>> Great. Thank you. The next question is coming from Nancy Schneider. She is saying that their state also struggles with multiple re-screenings occurring with infants, particularly infants who referred on newborn screening and have gone on to develop chronic middle ear disease. She's wondering what are some strategies you could suggest to encourage physician referral for diagnosis or diagnostic ABR studies in the children to rule out underlying sensory neural hearing loss.

>> Wow. Okay, let me see here. Now, so, hmm. I kind of see, like, two issues with this. You know, one is the multiple re-screenings, and that's been an issue for us as well, and sort of the way that we were trying to address it was, you know, with a lot of provider outreach in terms of the, you know, primary care physicians, you know, making sure that they, you know, understand that, you know, you've done the screening, and they failed another screening, it's time to send them off for, you know, diagnostic testing, stop re-screening,

and the way we've been approaching that is with, you know, outreach to the PCPs, which, you know, I do. I'm giving a talk, or at least I'm trying to arrange to give a talk at the next sort of large meeting of the Academy of Pediatrics in Louisiana. It's going to be in Shreveport, you know, to outreach to the primary care providers and sort of tell them, you know, don't do a bunch of re-screenings, just send them for diagnostic testing. So, that's one thing. I guess sort of the other aspect of it is, you know, making sure that when they are sent for re-screening, preferably that, you know, they sort of know what they're sending them for. So, I mean, if there's chronic middle ear disease, then perhaps the next, or the best thing to do is to send them to ENT and let them evaluate that chronic middle ear disease. So, I'm not quite sure that answers your question.

>> I'm not sure. I'll let her type more into the Q & A box.

>> Oh okay. Do children whose parents have confirmed hearing loss have a higher success rate for completing the audiological process? Um, you know, I don't know the answer to that. I would sort of suppose yes, because they'd be, I think, a little bit more, um, attuned to that, but, um, I don't really know.

>> Okay, great. Thank you. I apologize, I'm just kind of sifting through some of these other questions here

and seeing if there's ones that we have not addressed here. There's a couple questions in here regarding the power point availability. The webinar today has been recorded and will be posted up on the infanthearing.org website, so you will have access to the entire webinar, along with the power point slides. Okay, I think that's it. If you have any other questions, go ahead and type them into the Q & A box right now, and we'll just hold tight for just another minute and see if any other questions roll in. If not, we'll sign-off for today. Okay, let's go ahead and sign-off. Again, the webinar's recorded, and you'll be able to access it in about a week on the infanthearing.org website, and other than that, go ahead and sign-off. I appreciate your presentation, Dr. Choojitarom, and thank you so much, and we'll see many of you at the EHDI meeting in San Diego in a couple weeks, and if not this year, hopefully next year. Take care, everyone.

>> Would you like me to answer a couple of these questions in the Q & A? I think the study where we were doing it hadn't quite gotten to that area yet, because we were really focused more on the hearing screening, so I'm sure early intervention providers will be very helpful, but, um, in our study, that's not what we looked at. Then in our EHDI district in Georgia, we have many moms who deliver over the state line. Because of this, we lose the infants to documentation because we get the referrals for the babies months later. These also

have incorrect contact information. What can we do to reduce the loss to documentation in our area? That is not a new problem, guys, I got to tell you. We have that problem, of course, over in Texas. The closer you get to Texas, the more things get mixed up, because they'll live in Louisiana, but the nearest hospital is in Texas, so they go to Texas to have their babies, they do the hearing screenings, we never get them. So, it's going to require, and we've talked about this in our group, it's going to require a great deal of sort of cross-border cooperation. I think, or I'm hoping, that this new EHDI IS system will be very helpful in getting that to happen. Okay. All right, is there anything else, guys? Yes, it is mandated to report. Let's see here, in a case I have seen, the ENT was insistent the baby had an ear infection when he was, in fact, deaf. How better to handle this? Um, yet another ENT. You know, yeah, I don't, I'm not sure what to make of that, really. Is insurance a barrier for care? Do physicians need referral deductibles, etc.? Um, no, for the most part, these things are covered appropriately. Okay, so, incomplete audiological diagnosis or incomplete audiologic diagnosis, patient fails a newborn hearing screening, has one follow-up test, and is not loss to follow-up, not loss to documentation, so that's our definition of incomplete audiologic diagnosis.

>> Okay, I think you were able to answer all of

them. Great.

>> All right.

>> Okay, thanks again, and certainly, I'm sure that Dr. Choojitarom would be happy to answer any additional questions via e-mail after the presentation today, and we'll go ahead and sign-off. Have a fantastic afternoon.

>> Thank you, guys.

>> Thank you.

>> Bye-bye.

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