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CONSUMER: CASEY JUDD

EHDI

NARITA A/B – NEWBORN HEARING SCREENING: EARLY EDUCATION

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>> Good afternoon, can everyone hear us? Okay. So I'll just introduce myself and then I'll let Shannon introduce herself. My name is Lata Krishnan, I'm a clinical professor in audiology at Purdue University and I will tell you a little bit of background information that's relevant to this talk. I started at Purdue in 1998. In 2000 is when House Bill 1410 was passed in Indiana mandating newborn screening. I was there and helped set up our university clinic to be a follow up site for infants who fail their hearing screenings at the local hospitals. And so it's been sort of a topic that I say is near and dear to my heart. Over the last ten years or so I've had three different students who've done sort of their AUD capstone projects related to this topic and I've been their advisor on those.

This is a topic close to me and I'll just put that in a little bit perspective and then I'll let Shannon get started.
>> And I am Shannon Van Hyfte also a clinical associate professor at Purdue University and very involved in the newborn hearing screening program and I am going to share a little bit more about what Dr. Krishnan did because not only did she start it up but looked and investigated a lot of issues and has been vital and improving our own program so I want to make sure I give a shout‑out to that. So what we're going to be talking about today is one of those projects, the latest project. We want to first start by acknowledging partners who helped us with this. Our local OBGYN. Dr. Knutson and all the mothers who participated. There were more than 50 mothers who participated and filled out a questionnaire and did this with a 6 week infant in tow. So we will go over this information, share our rules, have some time for discussion and questions at the end. So as Dr. Krishnan mentioned the health bill 1410 passed in Indiana 1999 with full implementation in 2000 but it was JCIH that endorsed it. As you've heard a lot I'm sure in are already aware but the 1‑3‑6 goals are very important.

And we'd like to highlight a little bit of that with the screening at the age by age one month. Diagnosis of hearing loss by three months and intervention in place by six months. In this graph you can see that we're highlighting both the nation and Indiana because your state is important in where we go with this next project.

But both the nation and Indiana are doing very well with the screening. 95% of infants being screened and that's pretty comparable between the nation and our state. What I'd like to focus on is the loss to follow up, the identification of hearing loss by three months and the early intervention in place by six months. In our state, Indiana is doing better at loss to follow up. Our rates are lower than the nationwide average. Nationwide, we're looking at 25% loss to follow up and in Indiana, 13% roughly loss to follow up and we'd like to talk about why some of those things are in place that help us to keep a lower rate and we're still striving for better of course. Indiana's doing a little bit better than the nation in identification of hearing loss by the age of three months. Nationwide we're at 59% and in the state of Indiana, 71%. Thank you. And then enrollment in early intervention services by six months. Indiana is slightly better than the average. 72%. We could be doing better there but we're making good strides so the procedure in Indiana when an infant refers in the hospital they are rescreened, a second time if time allows. If that rescreening shows hearing loss then the hospital both refers to EHDI system and also schedules the diagnostic appointment before the family leaves the hospital at the facility of family's choosing. When a family chooses Purdue our procedures are kind of as follows. We do to acoustic emissions on every infant and high frequency tympanometry. We're seeing those babies at 4.8 weeks of age. That early age did decline, it got lower because the hospital schedules directly with the diagnostic facility. That makes a big difference. If we find hearing loss, we confirm that ideally within one week we also schedule that appointment before the family leaves our clinic.

And we feel those two things help with that loss to follow up rate, help us to keep track of the families, help make sure they know when the appointment is that we can verbally and visually give them that information. If we confirm the that we are referring to the first steps our early intervention program. We're talking about genetics. We're talking about vision, imaging, all the kinds of things that will roll out but we have those beginning conversations and set some of those referrals in place so we get them along that line. I'm going to switch a little bit now. Changing from kind of the general background information of our clinic, moving onto the background information for this particular study. So when we're looking at awareness and satisfaction with a newborn hearing screening program we can see from this one study there's a low awareness of the newborn hearing screening system that only a percentage of people called the screening and while that's a great point 87% of mothers supported it and said they were satisfied. They were less satisfied with the knowledge and information they had about the newborn hearing screening process. We also know the best time for communicating this information is before birth. But that most of that communication is happening at the hospital. And in fact, one of the students' projects and information we gleamed from that only three states have an informational brochure to tell parents about the newborn hearing screening before that. That's not to say certain facilities are putting that into place but only certain states are intentional about making that information known before the birthing process and we also know through a couple of different studies that a lack of knowledge and understanding can contribute to lower satisfaction in increased anxiety. So the aim of this project was really to look at whether or not providing expectant mothers education in the third trimester about the newborn hearing screening process would increase their satisfaction with the program. So we did this by looking at two groups. We had an intervention group of 25 participants and a controlled group of 25 participants. The OBGYN nurse provided the state brochure and a little bit of education to the 25 participants in the intervention group. She did that during the third trimester visit about two weeks before delivery give or take, there's a little bit of fluctuation there. The control group continued to receive that information in the hospital. And both groups completed the modified parent satisfaction questionnaire with neonatal hearing screening program. So this is the brochure, it's the brochure that families would get at the hospital. It tells brief information about the program, what it is, why we're doing it and provides information if they have questions of who they can contact. In addition we gave Kristin, the nurse who was giving this information an opportunity to have her own hearing tested so we brought our to acoustic emission portable screener. She found that to be super helpful, fascinating because she experienced it. She said that later on that it really helped her to better explain and understand what the babies were experiencing and so she could relay that better to mothers. We also gave her a script so that everyone received the same information and a list of frequently asked questions and the correct answers to those frequently asked questions so she was empower to do have that information. And all of that probably took us fifteen minutes. It was pretty brief. Maybe twenty. But it really helped to give her the information she needed to be able to share this. So a little bit about that modified questionnaire it was a five point like or dislike scale. There were six questions related to the satisfaction with the tester. So specifically about their knowledge, their skills, how approachable they were, how gentle they were and how much they informed the parent about the result. Six questions about the satisfaction of the procedure, how much time they had to wait, whether or not they were able to ask questions. Two questions about overall satisfaction with the program and then four questions with additional information specifically about the brochure, and information they were given and then there were some qualitative questions as well. And then I'm going to turn it over for results with Dr. Krishnan.
>> Okay. So hopefully you see this was really a rather simple project and we weren't necessarily expecting something really earth shattering to come out of it. At least I certainly went but we were quite pleasantly surprised with the rules. First some demographics. The mean age was about the same. 28.6 in the intervention group. 29.8 in the control group and again you'll see the range is relatively similar. 16‑41 years and 21‑44 years we also asked demographic questions about the mother's level of education and whether they were a first time parent and the first time parents I believe we had nine in the intervention group and ten in the control group and you can see that over here. The first bars. And then this looks somewhat variable in terms of, you know, high school, associate's, bachelor's and graduate school but when we combine them and so we call them sort of group A and group B. If we combine the high school and associate's over here. The two groups were relatively even and we actually did some statistics to compare and there are no significant differences in maternal education between the two groups.

One thing we didn't account for is that we actually got 50 ‑‑ well, 62 ‑‑ questionnaires but we had to discard 12 because the way we sorted the group was based on their answer to the first question.

I received information about the program from ‑‑ and if they had to check OBGYN and say they got the written information. And some of them they said OBGYN but didn't check written information so we ended up having to discard. I guess if I had to do it again that'd be something I'd look at a little better. All 25 infants from the intervention group passed the screening. In the control group 22 passed. Two were referred. One mother said she did not know. So there's maybe just a little inkling of the lack of knowledge right there. Of the two referred, one received written information and knew she had an appointment for the diagnostic already. The other one said she received verbal information and then she actually didn't check the box as to whether she had the appointment or not. So these are the results on the six questions about the tester questions one through six and then we lump them together to do the statistical t‑test comparisons. And so the tester was skillful, approachable, gentle, et cetera. You can see on every single question the intervention group is about one scale more positive than the control group. And when we looked at the overall six questions together that was a significant difference. Exactly the same story about the procedure as well so again the individual's six questions all better with the intervention group and when we look at the group comparisons the intervention group significantly more positive or more satisfied with the procedure than the control group. Here's the two questions and the overall satisfaction. Overall I was satisfied with the program or I was not satisfied with the program. So essentially the same question and, again, we have the same outcome where the intervention group were much more satisfied. Significantly more satisfied than the control group. Another way of looking at this is to see ‑‑ I'll pause a minute here. Okay. Another way of looking at this is to see how many respondents gave four or five as their check box on the like scale. So either agree or strongly agree. That was another way and the reason we did this is the original people who struggled this colleague they looked at it that way too. You can see the differences are very large in terms of tester more than 80% of the intervention groups had responses four or five meaning they agree or strongly agree that they were satisfied.

And only less than 40% of the control group. Again, 80% or so in the intervention group about the procedure. And about 40 on the control group. Overall satisfaction, 100% in the intervention group said they were overall satisfied with the program meaning they had a four or five on their scale and I believe it was 52% on the control group. And then we got qualitative data as well. That was the quantitative. And the qualitative questions there were two primary ones. One was, the one aspect about the program I was more than satisfied about and then one aspect of the program I was less than satisfied about. We got 25 total comments on the more than satisfied. 12 from the control group. And you'll say about equal numbers of parents in both groups said the tester was friendly, the tester was professional, the tester knew what they were doing, they were polite, et cetera. And also equal numbers talking about the procedure. That it was quick, convenient, but when you look at this bar here there were five mothers in the intervention group who said one thing they were more than satisfied about was that they knew about it. That they had the knowledge and zero in the control group. And then there were few I believe, three mothers in the control group who said that they were happy that the test went well that they were given their results that their baby had a rescreening when needed. The next question was ‑‑ that was what I thought kind of stood out to me. What were you less than satisfied about? And on this I find this most interesting is that the intervention group, they weren't really dissatisfied about much. There were two mother who is had a comment on this. When if we look at the control group we had ten mothers who wanted more information. We were not given any information. No one explained how the test was done. Someone said they took the baby and brought the baby back. I had no idea what happened and then there was another group that said they would have liked to have been present for the test. They didn't witness the test. We also asked for suggests, the intervention group didn't have many suggestions so they, again, it sort of matches that they were overall satisfied so they didn't have many suggestions for us. On the control group six mothers said they would have liked more information. So inform people about it. We never knew when he had it or how he had it done and then again, wanting to be there for the test, let the mom go if they choose. Okay. And then this part was not part of the original questionnaire. But we wrote it since we gave them the Indiana brochure. The who, what, why of hearing screening the three blue bars are intervention group mothers and we asked them was the content sufficient, was it easy to understand and was it very useful to have before delivery and you can see all those responses were very positive. So they brought the brochure was appropriate. They understood it. Interestingly the controlled group we asked them would it have been more useful if you had had prior information and they were kind of neutral. Three is that neutral range. Almost as if they didn't know what they didn't know. So I found that interesting because I was thinking oh, I wished I had known about it and that didn't turn out that way so in summary, mothers who receive information about newborn hearing screening prior to delivery and this was, you know, usually around that 36 week gestation appointment is when Kristin did this is already satisfied with more aspects about the tester, the procedure and just overall. Mothers would like to have the option to be present for the hearing screening. And mothers in the intervention group thought that the Indiana general brochure was easy to understand and useful to have before delivery. So what we're hoping to do is sort of disseminate this information, hopefully, so that EHDI and newborn hearing screening programs can consider sort of improving this but including education of OBGYN physicians because right now I know in  indie Yan that we do a lot with pediatricians. I don't know if we do anything with OBGYN physicians.

I hope that will become a piece of this and if they can share information with expectant mothers then the entire process may potentially be more positive. And then asking parents if they would like to be there for the screening. This may or may not be possible because I know the babies are whisked away, the mother may be asleep and so on. But perhaps a family member or making it known we're taking the baby for a hearing screening. And, you know, that might be helpful as well. Locally in the greater Lafayette area which is where we are, we've actually reached out to the physician, Dr. Knutson and have asked her to just continue giving these brochures out to her patients. And we've also asked if we can come to a lunch and learn or something along those lines with other physicians in the area so we can share this information and then, you know, I was thinking about this because I just came from another conference where I did a poster. Related to this topic. And my thought was we only measured satisfaction but certainly even handing that brochure, literally taking five minutes to improve their satisfaction, perhaps it will also be a factor in reducing loss to follow up because if they're more aware they know and maybe they will not miss that follow up appointment. And perhaps they'll be less anxious anxious as well. We don't know those things, but those are possible tangential benefits as well. That is all we have for you if you have any questions we're happy to try and answer. Yes.
>> Is this brochure available to use in other states?
>> I think we're supposed to, yeah, I guess I don't need that ‑‑ the question is, is this brochure available to use in other states? I believe every state, so, a different student Brianne did a project with me. I want to say three, four years ago 48 states have a brochure. Only two states have no brochure. Now what the content is does vary.

Some states have two brochures. A general brochure and if the baby has a positive another brochure. It's on the website, each state's brochure is on the website as well. Any other questions? Yes.
>> So I guess this study did not look at loss to follow up specifically. One of the things we experienced when our second child had the newborn hearing screening the screener told us it could just be fluid and we were like, no, no, no we have a family history. And so I was curious how that particular piece is being handled.
>> Yeah, so just in case you couldn't hear the question, the question was, that, when the second baby was screened the gener told the mother that it was probably just fluid in the ears. So this study did not look at those kinds of things but I can tell you both anecdotally we have definitely had that happen. I had a seven month old that identified with hearing loss and they only came in when the baby was seven months and said we were told it was just fluid. Fortunately that was several years ago and we're not having those kinds of incidents happen in the last few years. When we did look at loss to follow up, in one particular project that we did, we found that two things were contributing ‑‑ or, probably more but two things that we found one was that we were not being real stringent with our appointment scheduling so if a baby came in and actually did have fluid in the ears, we were saying go see your physician, there's fluid in the ear and once that's taken care of we'll schedule an appointment. We were losing a lot of babies. The second was that in Indiana when the baby didn't pass at the hospital, the referral happened to the early intervention first steps program and then first steps of course has two weeks to do intake and four days to get the IFSP. By the time the baby got to our clinic the median age was 8 weeks. So what happened in 2010 was that Indiana EHDI policy changed. Sort of, it was actually a funding cut to first steps which is a bad thing but it ended up in a good thing which is that Indiana EHDI policy changed and we're getting direct referral. We get the referral when the baby is one to two days old and the mean baby is 4.8 weeks and we internally after we had reviewed and found that we were losing 60% of these conductive loss babies to follow up internally our policy now is we do not let a baby leave without an appointment so we schedule it four weeks out or six weeks out and we keep seeing them again and again, four weeks, six weeks, until we have an answer. So those are two I think this is we have done to reduce loss to follow up. I do know that in Indiana our EHDI program does go around with training the screeners and such. I don't have enough information about that as to how frequently it happens. I can tell you also that the student Brianne who looked at the brochures across the states,only half the states who have a brochure include at least one reason for why the baby might have referred or failed a screening. And only twelve out of the 50 states have a brochure that includes all four common reasons for why a baby refers which would be the baby was fussy or noisy or the baby has fluid in the ears or the baby has hearing loss. And only twelve out of the 50 states have a brochure that spells that out. So that's certainly something, you know, place where we could do better. Okay. Thank you so much we appreciate your being here and the questions.
>> (Applause).