REALTIME FILE

EHDI

INTERNATIONAL D&E ROOM

NEWBORN HEARING SCREENER SENSITIVITY TRAINING:

WHAT WE OFFERED/WHAT WE LEARNED/WHERE WE’LL GO NEXT

MARCH 4, 2019, 3:35 P.M.

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>> We're going to get started. It's 3:35. This is newborn screener sensitivity training, what we offered, what we learned, where we'll go next.

>> We are the last session. Hope you're excited about another presentation. We are, and we hope you will be too. So my name is Linda Bowen, I'm a speech path with North Carolina EHDI, and with me is Jude Williams, and she's the grant coordinator, and we'll talk to you about a project we did in North Carolina, so we'll give you a little background. Here are the learning objectives, to be exposed to innovative methods of training with community partners to enhance family outcomes.

NC EHDI, we both work with North Carolina, with the EHDI program, and we support, promote, and monitor the newborn screening hearing diagnosis intervention process. We provide consultation, technical assistance, education, and training, and we are large, and we are able to do a lot of things. So we have an EHDI coordinator, Marcia Fort. I don't know how many are familiar with her. There are 11 of us in the region, and I'll show you a map in the second. We have a parent, and Jude is our grant coordinator, we have a follow-up and an administrative assistant. We are large, but we're doing a lot of stuff. So just know that.

Here is a picture of our map, and we -- in North Carolina, we use this a lot to help with talking to folks in our region, explaining where things are, where are the locations of resources can be found, and it does show up in purple. I'm in the purple. Good UC Pirate country out there. I don't know how many of you know anything about North Carolina. We have the UNC Chapel Hill area, that might be a little bit of a Carolina blue color in there. So we have different regions with different resources. The east and the Western part of the states, the purple part over is the outer banks there on the far right. And then the Western part of the state are outlying areas with limited resources. The middle parts of the state where the four counties with the red and the Mecklenburg County down there are the most populous areas and every area is a little bit different and there are different pros and cons to the different regions.

Some of the state facts for North Carolina, we're the ninth most populous state with 10.3 million residents. Our birth rate is around 123,000 a year. So that puts us around 217, that was in 2017, 217 babies diagnosed with hearing loss. Loss to follow-up or loss to documentation was around 34% and we have 88 birthing facilities. So that gives you a background of where we stand. So one of our issues that we always have is communicating what we want from the EHDI program to our stakeholders and in particularly in this presentation, to those 88 hospitals.

We are lucky in North Carolina to have a lot of resources also with our stakeholders and the CARE Project is a part of that. Is everybody familiar with the CARE Project? Okay. There's another presentation right now about the CARE Project, so it's being implemented in our states and other countries, and that's fantastic. We're lucky to have Johnnie Sexton in North Carolina, and in 2013 with the impetus of our training that we did, we had -- North Carolina EHDI hosted a care project and 22 professionals and parents of hearing loss came to that workshop. The topics were adjustment counseling, the parent journey, stages of grief, strategies for professionals, which is pretty much what the CARE Project encompasses, so we brought in the professionals also. And there's a lot of review of documentary film segments, and there are families sharing their stories during that time.

So following that, that retreat, the -- one of the folks that was there was Laura Hall, she's pictured here. You fill out the evaluation and you say it was a great day and we had a great time and I so appreciated it. This lady, who works at one of our hospitals, she is contracted as a hearing screener, sent Johnnie a personal email, and you can read it, and just take a minute. Just kind of sums what the experience meant to her and how much it meant to her to look at the parents affected. So just take a second for that.

We kind of had an aha moment at that time because we had heard it from the CARE family stories. We had seen it and heard it from the EHDI partners in North Carolina, and a lot of the folks that we're talking about, which is dovetails from a presentation in here this morning about hearing screening curriculum for hospital screeners, and that goes more into the technical side of things. We were looking at going more into the sensitivity training side. What are the screeners telling the parents? What message are they receiving? A lot of times they hear, oh, it's just fluid, don't worry about it. And that's understandable, because they want to appease their worry, but they need to be able to sensitively give bad news. So the aha moment was what the CARE Project workers had talked about, what the EHDI parents had talked about, and what Laura Hall saw in the hospital. So we decided to design a sensitivity training for newborn hearing screeners.

This was our committee. We had Laura Hall, who was from the community, John Sexton, Holly Shoun, Linda Bowen, myself, Marcia Fort, Jude Williams, and Emily Burt. We started meeting in the summer of 2016 through the fall of 2017 to develop our content and select the videos. We got the consent from Emily Perl Kingsley to use the "welcome to Holland" Poem and we developed a 30-minute video and inserted open captions. It premiered last year at the EHDI conference, so I think some of you guys saw it. And I'll dovetail saying that our presentation is about 30 minutes, and it dovetails really well with some of the other technical things that folks are exposed to.

If you would like to outside of the session, if you'll go to YouTube and look for NC EHDI and the CARE Project, you can find the whole 30-minute video. We're going to show some clips for it and show you some slides to give you an idea of a glimpse of what it's like.

We go through hearing loss facts, speech and language development, the EHDI 1-3-6 goals, the essential role of the hearing screener, the stages of grief. We touch on loss to follow-up also, which is not included in this bullet. And sensitive ways of sharing or referring results with families.

So here is one of our slides. This is kind of the look of it. And you can see down at the bottom, the captioning. So one of the things we pointed out -- some of the things that we mentioned were things that are -- to us in the EHDI world are well known and obvious. For those of us that have been in it for a long time. But for hearing screening personnel that are turning over rapidly and it's not all that they do, EHDI is what we do, for the nurses in the hospital, it's not what they do solely. So I think we need to remind them of that, to bring it to the forefront to them and highlight the key topic. One of the things, it's the most frequently occurring congenital condition, two to three out of every 1,000 children in the United States are born with hearing loss, and we talked about hearing loss greatest in the first three years if not exposed to language in the first three years, children have a greater difficulty developing language.

So while these slides are progressing, the captioning is at the bottom, and Johnnie Sexton is the narrator for the video.

And one of the things that we really wanted to drive home was the essential role was hearing screener. They're the first professional contact that the families have, and as we've heard time and time again, they're the people that start the families on their journey, and it's so vital for them to present a positive response because that lasts. That image lasts, and we've heard -- Jude and I were talking about it earlier. It's like they remember that person. And they're the person that's the first person on that journey. And if they have a good impact on the family, then the outcome is going to be a lot nicer for the whole journey, the family and the child.

Here's another, we talk about the stages of grief. And with our person that was able to do the video, we were able to do a lot of little neat things with the emojis and different responses, so we go through the stages of grief. We go through -- there again, we're going through how to talk with families, how to talk with parents, hitting the pause button, don't just go run of the mill, hand it on, on a brochure and leave the room. You need to take a little more time and talk with the parents and -- we kind of went through a little bit of ways to do that, to just be a little bit more sensitive.

So here we have my favorite portion of the entire video, which was initially produced by NCHAM, and we borrowed that with permission. So we're going to show that to you. You can get a good idea of what the training looks like, how it sounds, and just kind of encapsulates the 30 minutes with this one little snippet. Here we go.

>> And just to let you know too, there are many videos, parents sharing their story within the 30-minute training, if you go on to the YouTube, you'll be able to see it in its entirety.

(Captioned video)

All right. Thank you for your patience with that. We will move on quickly to answer your questions and probably others. So we, like I said, it took us a while to create this video, so we wanted to be very particular about our dissemination plan. We wanted to be certain that we used QI methodology. We wanted to have a pretest and a post test so we could look in change in knowledge based on the information we were sharing with the screeners in the video, and their evaluation of the video itself.

So we initially sent it out to three birthing facilities and asked them lots of questions about the video, if they would use it with the screeners, and we had very positive feedback. At that point, as a team, we decided we would move it from that test to a full statewide dissemination. They all had relationships with all of our birthing facilities, so they used their contacts and basically through email dissemination and a call shared the video as a YouTube link in the email with instructions on how to access it. And we have encouraged our birthing centers to use the sensitivity screening in the competency screening and in onboarding any new screeners.

It was important for us to have a buy-in or a hook for the hospital in this training, and we did have an annual compliance and in there, there is a training requirement so there is something they could use for that purpose.

I'm going to go through what we learned. We disseminated it last summer and about 770 screeners are registered to take the training and 64 of 88 have been able to use it. We've had almost 1200 views on YouTube, as it is in a public space, so other states have actually shared it and used it as well.

Just quickly, we had a six-question evaluation. We wanted to ask and know if the training gave them practical ways to share newborn hearing screening results with family, if screeners felt more confident after viewing the training, and whether or not the personal stories that we presented actually helped to convey and support the message we were trying to relay. And importantly, would they recommend the training to someone else, another peer trainer. And we also asked some open-ended questions.

Looking at all of those responses, we had more than 90% who agreed or strongly agreed that yes, the training gave them practical ways to share the screening results. They all felt more confident in sharing results and they would recommend the training.

We did ask them, did they have other training needs that we could also address in another training, and a lot of them wanted more technical training. They wanted more on the screening skills, what affects the testing, how can they reduce the ambient and myogenic noise, the auditory brainstem response works, role playing to how to respond to parents' questions, and how to care for a Deaf infant and more about Deaf culture.

We also had some comments or suggestions on ways we could improve the video. You can see the sample size is pretty small, but we do take everyone's comments and look at them. Some thought the video was too long. It was 30 minutes. A nurse that was it was too basic. There was some comment about the pace, hard to remember the statistics, that there might be too much information for someone doing the initial screening in the hospital, and we also had a comment about too much information on the grief process.

Like I said, we did a pre and post test for difference in knowledge. We had 80% get a score of 80 on the pretest and that changed to 98% on the post test. You can see the sample size is quite different for the pretest and post test and I'll tell you about that in a minute. This is small. You can't see it. It's a pre-post test.

The greatest change in knowledge, what is the most common occurring congenital condition, that was 91% in the pretest and 98% in the post test. What percentage of Deaf babies are born to parents that can hear, 40% selected, 90% is the right answer. After they watched it, they said 90%, and understanding loss to follow-up rates, 47% who knew that North Carolina's loss to follow-up was 34% but that increased to 97%. And as Linda was explaining, the knowledge and the importance of their role in helping us reduce loss to follow-up is very important.

Just quickly, some lessons learned. Our birthing facilities were interested in providing this information because it was easy for them and met their needs and our needs through that buy-in through the compliance guide. Like I said, newborn screeners want to understand more the technical aspects of their work.

Now, we did have some birthing facilities who were resistant to the training because some do not allow outside agencies to provide those trainings. They want to develop their own internal training. So some said no, we can't do that. And YouTube, not all hospitals can access YouTube at work, so we did have to provide on a thumb drive or a CD the actual training. Some birthing facilities watched employees to watch the video at work as a part of their work assignment and others did not and would ask their employees to watch it at home. Again, we were not monitoring who did or didn't from the EHDI program site, but we just made it available.

And importantly, to learn and act on what you learn from your partners. Laura Hall is the impetus for this next step, and we're happy to have this training.

The training package is a bit cumbersome, that's where you saw the number of screeners taking the pretest and the post test. We send it out through a gizmo link, they had to return to an old email to get the post test link and the certificate. About 50% went back and did the post test. So next steps, one of the things we're trying to do is figure out a better way, to make it easier, to manipulate the presentation package.

Where are we going from here? As I said, this was a great learning year. We're going to talk with all of our birthing facilities during our compliance about the results and hopefully ask them some very specific questions as well about using it as a training tool within their organization. We hope to share the training with other screening personnel including midwives and health departments, streamline that distribution training package and we have an education training committee, so shared those additional training requests so that we can move forward on next steps.

And importantly, we have in the past year developed a pediatric audiology sensitivity training very similar to this. We premiered it last weekend at our North Carolina CARE professional parent collaborative. Once we set up the pretests and evaluation, we will make that also publicly available for anyone to share with their audiologist in their city.

This is a quote from one of our participants. I know we're running short on time. We plan to keep it up. We plan to keep trying to meet the needs of our screeners, our audiologists by engaging our stakeholders, our parents, and the target audience.

>> Do you all have any questions? Thank you for your time.

(Applause).

>> I know that has only been implemented since last summer, but are you seeing any changes in your direct loss to follow-up numbers as a result? Are you seeing any difference in referral rates, anything like that, since this training occurred?

>> That's a good -- Linda and I were just talking about that before we started. We have not looked at that yet. But we do need to figure out some way to make sure that, of course, training seems to be welcomed by the newborn hearing screeners, but is it making a difference? Is it improving the communication in the screeners and the parents, and ultimately helping with loss to follow-up? We can look at which hospitals have completed it and has there been a change, but we have not done that to date. But it's a good suggestion.

>> This might be a little farfetched of a question, so it's okay. But when I saw that it was sensitivity training, one of the reasons I was commenting is because we've been doing a lot with health equity and thinking about how systemic oppression happens in the healthcare setting almost more than anywhere else and thinking about help literacy and help screeners kind of bridge that divide and like what methods they can be using, teach that, and make sure the families understand that -- they're not just delivering in what they perceive in a clear way but that families are receiving it in a clear way. I haven't watched the video yet, so I'm wondering, have you embedded some of that sensitivity into the training?

>> We talk about methodology and percentage, so like pausing and letting families ask questions, not about rushing into all the information right up front. And giving them written information along with verbal information. That's about -- (away from mic).

>> Marcia. She can help.

>> MARCIA FORT: Hi, this is Marcia Fort, I'm the EHDI coordinator for this group. We have not specifically looked at incorporating health equity, but I think we will moving forward, see if we can incorporate that. That's kind of across our title 5, which I think is probably happening to you too. So we probably will look at incorporating some of that into future videos or edits on the ones we have.

>> AUDIENCE MEMBER: Thanks.

>> I just want to know where all these training videos -- are they in one spot or we Google it -- I just want to be able to get to those trainings quickly.

>> They are right now on the -- they are located on the CARE Project YouTube channel. You can go to the CARE Project site.

>> You can just actually go to YouTube, if you don't have the site which was in the presentation, you can go to YouTube, put in the keywords CARE Project NC EHDI, and it will have the little symbol, and you'll know it's the right one. And feel free to use it.

>> Time for one more?

>> AUDIENCE MEMBER: What was the cost to produce the video?

>> It was about $6 ,000 for the development of the video, including the captioning.

>> All right. Thank you.

(Applause).

(End of session at 4:08 p.m. CT)