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CONSUMER: CASEY JUDD

EHDI

NARITA A/B – PARENT SUPPORT IN A HOSPITAL SETTING

MARCH 5, 2019

CART CAPTIONING PROVIDED BY: SHERRIN PATTI

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>> We're going to go on and get started. It's like, one minute. We ready? Okay. Well good afternoon, everyone, my name is Rachel Stough and I'm going to present briefly on our parent support that we provide in a hospital setting in Tennessee. So you're learning objectives today I hope that you will learn a new opportunity to engage families and family support organizations learn how family relationships influence state EHDI systems. Know how state EHDI programs justify their funding methodology and then some lessons learned from Tennessee so quickly an introduction my parent's journey I will try to be brief. Any parent can talk all day about what their experience was like with their child. Through the EHDI journey and I have two children. So I could probably spend a couple of days. But the ‑‑ my first son was not he did not pass his national newborn hearing screening and I went to my primary care physician and I was told I have to follow up with you and he said 50% fail their newborn screening. He says I'll do a referral if you want.

I said no, I trust you. Right? That relationship was there and so he was identified much later at around eight months after I went through several providers and had a parental instinct that something wasn't right. He wasn't meeting his speech and language developmental milestones so the picture is Harrison holding my daughter Victoria and if you'll see she has a hearing aid hanging out of her ear. She has about ten days old in this picture and she passed her initial newborn screening and so I was so excited and when I got home from the hospital my family audiologist called and said, Rachel, can you bring Victoria in for more screening and testing and said, oh, Kathy, she passed her hearing screen, we are just fine. And she said, please, Rachel, for the risk factors with your family bring her in. It was at that time within one week of her being born that she was identified with a cookie bite loss if audiologists are aware of that so she over the course of her first year of life lost all of her hearing so we aided her so we could get all the residual hearing and benefits of sound that we could and so they both have bilateral cochlear implants and they're 12 and 14 and are doing fantastic but see the picture of me on the left I'm super stressed. I'm very upset and one of the loneliest times parent has is when they find out their child has hearing loss and that natural support system that you have either your mom or your dad or your really close friend, there's nobody that you can call and say, what do I do now? Because they don't know. So it's one of the loneliest times I've ever experienced in my life and I'm going to make it one of my missions to make sure that we can decrease some of this loneliness that parents feel. So parents have a lot of relationships, some that are natural and some that have to be created after their baby's been diagnosed with hearing loss so the first one is the parent child relationship. I'm very happy in this picture because she passed her hearing screening and she was going to be the perfect language role model for my son and the foundation for social emotional health and wellness for a baby is the security and attachment to their parent. So when we look at this relationship with a parent and providers that same trust is very much an active part of the success of how the family's journey evolves with EHDI in their state. So my relationship with my providers I trusted her, I believed every word she said I did everything she said and then I'm also looking at how the parent is involved in the state EHDI system and I was very lucky to be a parent guide before I was an EHDI coordinator and so this is a picture of the EHDI conference. A few years ago I didn't know there was an EHDI. I was really excited to be a parent guide and then to meet with them and collaborate with them, but every relationship is really requiring the same trust and communication. So the frequency and intensity of these relationships is all associate ed with the EHDI journey for that family so a parent guide in the hospital setting is really addressing all of these relationships at one time. So family voices perspective PEARS is our family wide support organization.

They have parent guides that provide that individualized PEARS support for those who are deaf and hard of hearing. Melanie Lindsay is in the room if you have any questions with her afterwards. So while all this was going on with me personally as a parent what was going on in Tennessee? In the EHDI system here? So in '96, we started a newborn hearing program with HRSA funding and we were able to get an audiology consultant on board and one parent consultant. Around 2002 hospitals started reporting results to the hearing health. And then in 2006 a hearing screened occurred without a mandate and then it became a mandate. My son actually went to school with Claire and we shared the same speech language pathologist and I will never forget sitting in speech therapy and her saying guess what Claire's mom did. She got mandatory screening and I was like, wow, that was great. I wish I could do something, kind of work at the state. So that was back in 2008.

So then we had the opportunity to have some CDC funding on EHDI and are tracking data and information system so this progressed in 2011 where we had a statewide family support contract. This increased the number of parent guides that were provided within Tennessee disability coalition and then housed within central office in 2010 we had a quality improvement office so the way that the Tennessee Department of Health is housed within the newborn hearing screening program, we have nurse case managers. They receive all of those hearing screening results and they are calling all the PCPs and hospitals and providers. And doing that in‑house so we don't have to contract out for those follow up services but we did continue the contract with family support. So then in 2017, we expanded central office, we have a nurse health educator that goes around and talks with hospitals. Who are needing some more technical assistance on how to report. And then that's when I came on board. In 2017. And I met with Melanie Lindsay who I had the honor to work with as a parent guide and she had a dream for five years that she wanted to have a parent guide in a hospital setting and I said, what a great idea. So, but at the state level I had to justify this. So how was I going to be able to justify this great idea? In 2018 we did get that first parent guide established and the hospital and March of 2018, I'll talk a little bit more about the system shortly but I wanted to share with you what our collaboration looks like with parents across the state. You have parents of children who are deaf and hard of hearing that attend many different family support events across the state. We have our contracted family voice's PEARS organization that receives all of those referrals immediately from central office once that child has a confirmed hearing loss I have five regional task force meetings across the state that includes parents and additional family support organizations and then central office, myself as the EHDI coordinator. So when you justify ‑‑ when I had to look at justifying this funding I met with an epidemiologist and we looked at those loss to follow ups so we had more than 2700 infants who did not pass that initial hearing screen and received diagnostic testing from a very large children's hospital.

And that region of the state. So among those 317 with hearing loss were confirmed which is accounted for about 20% of all hearing loss instants diagnosed. And I also looked at our existing referral system for parent support so right now while we send that referral immediately to family support it takes them a little bit of time. 24‑48 hours they'll either create a letter with the picture of the family guide or they're placing a cold call to the family and while that's a two or three day break, I know what the loneliness feels like for two or three days and we want to eliminate that as quickly as possible.

And I had some carry over funds so I said, let's figure out how I request use this data and support this project. Really how did we do this? It was a process and it was based on relationships and what's the foundation of a good social emotional foundation? That's trust. That's security. That's attachment. What are your connections?

So we met with Melanie who identified some existing relationships that they had. My thoughts were we were going to work on birthing hospitals because I wanted to address screening to diagnostics. But she had a really strong relationship with the director of audiology in this large children's hospital regarding loss to follow up and them talking about the need for family support that region there's only one diagnostic hospital for that whole side of the state so parents were having to drive several hours. So the parent guide need to complete a volunteer program and it needed a background check. So that took us a little time. And then the audiologist set up a private meeting room for the guide and the patient and family to meet together. So there's always got to be data and what's happening with this really cool program, what's happened, what kind of services are families really getting? With our family support organization they always complete a quarterly report to me and we look at how many parent guides we have. How many services for hearing loss were provided based on their diagnosis. What kind of outreach and education was attended? How far did they have to go? How many health care providers? It is an exhausting report that they complete for us each quarter. So I had to ask for another report. And I said, Melanie, these are really great numbers but I need to know exactly what's going on in that hospital. What kind of activity and progress is Leah having with these families so she created one for PEARS and it looked at who was getting that direct parent to parent support, there's a number of families that had follow up home visits and then who came for follow up and you can see in March, this is when we just started. We were at ‑‑ around four families provided services as of December it was 39 families and it's gone up since then around 98 as of now so it is growing exponentially. My quarterly reports I got it in December. So she's here with more current data but for what was ‑‑ what was sent to me latest for the presentation was then. So some lessons learned is it did take a little bit longer with the hospital to work within all of their security. So you're going to have to find out are there volunteer services that you can go through, what is the background check? But we saw that family compliance with audiology appointments improved. There were some people that had come originally and they would never be able to find the family again. They started coming more often for those follow up appointments and then my benchmark justification changed and I didn't know this was okay. But it's just what it was. So while I thought I was addressing that screening one to three month benchmark I was really addressing once that child was diagnosed and how they were going to be reaching that six month for intervention. We also looked at a warm transfer from the audiologist to the parent guide and I had mentioned this earlier. It's been referenced in some other presentations. As a therapeutic alliance. But it's really ‑‑ because families are on this journey, they find people that they have to trust. And so many times the audiologist is providing that medical expertise and I don't know if you hear this enough but audiologists change lives and you're seeing these newborn babies and you're effecting people's lives forever and you might not always hear families that can come back to you and tell you how wonderful you are so I think I'm okay to speak on their behalf and say thank you so much for being there. Because they remember every word you say and they hang on that. So that emotional support that you provide them, what we have found is that when an audiologist talks to the family about parent support and let's them know that someone right around the corner is available for you to talk to next, then it's providing that immediate comfort. Originally they had ‑‑ it was with lessons learned but originally they were just asking the parent, did you want to talk to someone? And parents were traumatized at that point. Some of them, some of them are full of joy if they have a family history and they're comfortable with that but if it's new they don't know what to do so they made it part of their visit. After they finish diagnostics they just made the parent guide part of that audiology appointment. So we have many partnerships. This doesn't happen from one or two people. We thank HRSA and CDC and all of the audiologists, our hospital that was willing to let us come in and try this pilot. And then we have University of Tennessee who is our audiology consultant and our deaf educator and then of course family voices and we worked very closely with our Department of Education. Which is where our early intervention services are housed and then we have a contract with five universities across the state with audiology students. If we don't get follow up information from hospitals or providers, we send follow‑up letters to students. And students make an extra effort to call the parent or provider and get more information to see if we can find the families. I'd like to thank Melanie Lindsay and Liam Williamson and thank Dr. Bidelman. She is the director of audiology and Dr. Li who is our epidemiologist on staff. We have a couple minutes does anyone have any questions for me? It is ongoing so this was first year but it'd be ongoing.

With carry over funds and we are looking at how we can put parent guides in other hospital settings. You have to have a relationship. So trusted people you can talk to that feel comfortable with someone who is not a hospital employee coming in to work with those patients. But they are and Melanie you might want to speak to that but I know they're working on relationships with some other major diagnostic right now ‑‑ hospitals right now. Any other questions?   
>> (Speaker far from mic).  
>> Once my nurse case management staff has exhausted our resources at some time we have to close as loss to follow up. I worked closely with Julie, not me, the EHDI coordinator before at University of Tennessee and she thought it would be a great experience for audiology students to learn to talk to families about that and she created a script for students and we do have a no cost contract with these universities so that HIPAA is included to make sure that we are all being compliant. But they make those calls to families and then if they collect that loss to follow up information they send that back to me. And because this ‑‑ that's a no cost contract with these five universities, students are doing a lot of work for us so I created a superstar award when I see that a student is sending me information, they give us back a lot of information. Maybe a family got a new primary care physician. Or they have moved somewhere elsewhere we could follow them more closely. If they send me any additional information then I make a certificate out of a shining star award and I sign it and send it to them. So thanking them for that work. Any questions?  
>> Just curious, what kind of information do you share when the parent ‑‑ so I just want to know what kind of information is it that you share with the family when you meet them at the hospital? Do you have a list that you follow a guide? What is it ‑‑ what does that look like?  
>> So and Melanie is here if she wants to add more but when a parent the traumatized and they're just finding out the news they could be very happy. They could be very sad. They could be in a state of shock. So it really relies on what is the mental state of that parent as to what information is given to them. What makes our family support organization somewhat unique is that they move at the pace of the family. And as a parent guide I can tell you I've been in homes. If parents are in denial and you're throwing them education go here, go here, if they're in denial they're not absorbing that information so there's some questions that you can ask them based on where their stage of acceptance is with their child that will determine how to move them along. So it might not be throwing them all the resources but saying, what do I do next or I'm sad and they need someone to be sad with them or they say I'm so excited wait until I call my uncle because he's deaf too and will have a connection. So you really can't put a stamp on an approach to working with a family. It's individualized and it's based on what the parent needs at the time you're meeting with that parent. Okay I don't see any other questions so ‑‑ oh, yes.  
>> (Speaker far from mic).

>> My epidemiologist is here. We got the data so the question is based on what those loss to follow up rates were in 2017, have we seen in a reduction in the loss to follow up? So ‑‑ this is our epidemiologist. My number person.  
>> Because this is a relatively new project so we don't have data at this time to look at the effects yet. But everything is in our data system so later in this year we can look at specific for that hospital. Which is large hospital in our area. So I can look at those data later on so maybe that can be something for next time.  
>> Yeah. Any other questions? Okay. Thank you so much. If you think of something afterwards feel free to give me a call or e‑mail me. Appreciate it.  
>> (Applause).