ROUGHLY EDITED COPY

EHDI – Florence

Putting the “I” in EHDI – Where Do We Go From Here?

Casey Judd

March 4, 2019

11:15-11:40a

CART/CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

[WWW.CAPTIONFAMILY.COM](http://WWW.CAPTIONFAMILY.COM)

"This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings."

[Captioner is standing by waiting to connect audio].

[The captioner is standing by].

>> Is this working? Okay... for, for the folks in the audience, I'm going to use my L1, which is broken English, just so you know. We have interpreters here for communication access. So, my name is Dr. Robert Nutt. I'm a developmental and behavioral pediatrician in North Carolina. I practice full‑time and work with kids in that specialty, which is mostly kids with autism, ADHD, anxiety, genetic conditions, such as Down Syndrome, the DUETT syndrome and others.

So... welcome. And I'm going to let my colleagues introduce themselves as well. And then we'll tell you how this presentation came about. I hope you learn a lot from us. I'm going to let ‑‑  
 >> My name is Jessica Hoffman. I'm an audiologist in Westchester, New York. I do cochlear implants, hearing aids, diagnostic reviews, everything. So... I've been in this ‑‑ I've been practicing as an audiologist since 2010 and had an awesome stint in United Kingdom for four years and then I moved back to the U.S. in 2014 and then I started working for this ENT practice in Westchester Medical Center and will be setting up the Westchester Cochlear Implant Program, which is very exciting. I'll now pass the mic on to my colleague.

>> Good morning, everybody, I'm Karen Hopkins. I coordinate services for children birth to 21 and I'm also the Principal Investigator in the state of Maine as well. So... many different hats. I'm also a parent of a hard of hearing little girl ‑‑ that's myself. Many, many hats, the three of us have. The idea for this presentation came when Rob and I met in Austria this summer. The conference was done and... last day we were in the country of Austria, we decided to kill some time, because... all of our colleagues were in a meeting and took a ride up the gondola. We were talking about the amazing affects of that conference and really focused on family‑centered learning, family‑centered care, infusing the deaf and hard of hearing perspective into all that we do and say... and we said... hey... we should do this. We should do a presentation. We were talking about the 1:3:6 of EHDI. Thinking about the audiologist perspective and intervention ‑‑ so... here we are ‑‑ we hope you find this enlightening. We have nothing to disclose objection the than we paid for this by our jobs and that's all.

>> Robert: I prefer to stand so I can see you all. So... yeah... Family Centered Early Intervention is a wonderful conference, similar to EHDI. But it lends an international voice. Those of us who do attend and are part of the conversation on the global level, it's a wonderful experience. We bring that back to you with the kind of language, tone, the collegial cooperative, very positive and so... Karen and I were like... how can we bring this back to EHDI? And... so... that begins today... so... those of you that have been involved in EHDI, and those of you who are new ‑‑ the numbers are up, the funding is down... at least in terms of the medical centers and the community hospitals, we are finding, you know... 90% of kids. We still have issues with follow‑up. So... we have the E, we have the H, D and especially for those of you who are able to attend Nasser, we're really starting to get into the I. Some people proposed the I be separate. Maybe branching off and continuing those conversations in a more practical way. Leaving a lot of the numbers and CDC data, et cetera. To be left to those folks who are interested in policy and numbers and the more practical, educational, familial approach of being separate.

The early intervention has a segue into the life of a deaf child. We ‑‑ I think we would go backwards in terms of polarity of our discussion. That's one point I want to make ‑‑ all right?

So the the focus on our presentation with the I in EHDI is language. If you think about it, as a developmental pediatrician, I'm not talking about what the child does, I'm talking about how the child does it. I'm not talking about what the parents do ‑‑ I'm trying to think about what the parents and educators are doing ‑‑ how is that affecting the development of the child? Development is a manifestation of the child's brain. How the child's brain is functioning and how the child's brain is connecting. Language is our ‑‑ these pictures... suggest... not that one. I uploaded the new version before I came over here ‑‑ looks like we have one of the older versions, but we'll make do. Forget the Google image, the Google image is there too.

So... language is a mode of communicating what is in my brain and I want you to get in your brain, okay? And... it doesn't really matter how it gets there. It's important for your messages to reach my brain and my brain to process that, to make the neuronal connections over repeated exposures and to learn.

If you think about difficult conversations that you've had in relationships, often misunderstandings, and that's a picture of the ‑‑ with the black and the orange, that I have an organized thought and sometimes I communicate it and it's not received well. It's misunderstood or the other person, based on their own experiences, may misunderstand it.

So... these are all issues we deal with in deaf and hard of hearing kids. I've had many experiences in my clinic as a developmental pediatrician. A parent will come to me and I demonstrate how much their child doesn't understand. I do that by showing them ‑‑ I simply ask the parent questions. That question... in their language and it they answer me back. Okay? They're not answering questions directly, they seem to always talk about what they want to talk about. I have to make that distinction between autism and deafness, autism in a child who is not answering my questions because they're not doing it.

And... you know... I show them the deaf nod, you know... yes... no, I don't understand you. Okay? But I'm faking it until I make, it okay? If you're deaf and hard of hearing, just go through this kind of fractured language, you know... this kind of picture, you know... instead of the idea being from brain to brain, we get into this ‑‑ it doesn't matter your language modality or language choices, even people who are hearing persons, in spoken English ‑‑ you're still misunderstanding each other, right?

So... as my wife likes to say, we sign that, I said it, it's signed, you saw two ways to get it and still didn't get it.  
[laughter]  
 >> Robert: So, language is a complex modality and something that is very important for us to talk about when we go forward with the I in EHDI, okay? We want to emphasize together today, this is your baby, this is your client, this is the child who comes into the world. Okay? The child is a beautiful, perfect being, in and of themselves, okay? Yes, they get tests, okay? They get their hair pricked, they get weighed naked, they get suctioned, if they need to. So... but... we do do tests to find out what the baby needs and that's something that we've had a very successful job doing on the national level.

But... we come back to this picture because this is the baby. This is who we're talking about, we're not talking about a child who is hooked up to an ABR, okay? We're talking about a child who is whole, who is in and of themselves, okay? And I'll show you what's in the [indiscernible] with us. I'll hold it up, okay?

>> Keeping that baby in mind, I'm going to ask that you ‑‑ boy... this is really confusing. Please just watch this slide. All those woods. The family in the middle. That beautiful baby you saw. That's what we do. We go into these families homes and we're bombarding them with language, opportunities, appointments, broken language, ASL, cued speech, make sure when you're working with these families that you keep the families bigger than anything else. And remember ‑‑ it's a journey. These families, from the minute they meet you, no matter what your role is, an audiologist, a pediatrician, early interventionist ‑‑ you're on a journey with each family. There's not a one straight road, it's windy and curvy and oftentimes, quite bumpy. The professionals in the room, we have to remember, when we enter any this journey with the families, they have feelings and a lot of expectations. They have opinions, they're getting a lot of information from families, from the internet, from colleagues. Open up a dialogue. Build respect with them and that will lead to [indiscernible] together.

We focus a lot on language. And communication. But... we focus on these areas in communication, knowledge, thinking, social skills and literacy. I think you'd all agree those are really important for children to learn. The two Ns that we focus on are visual learning and spoken learning.

We don't focus on one or the other, we provide all the options. It's really the journey of the family and the choices they make that help them find the right path for their child and baby. I'm going to turn this over to Jessica to talk about audiologists and then we'll come back.

>> Jessica: A brief overview of what audiologists do, within our scope of practice, so... the first main thing is the identification and getting it in ‑‑ the baby in the door as early as possible, the final diagnosis by the age of one month and be fitted with proper amplification, whatever is needed at three months and really be in the EHDI and all the treatment by six months. As an audiologist ‑‑ it's part of our job when we tell the families what the diagnosis is, but we also need to tell them what the potential plan, the ‑‑ what to do next. They're obviously ‑‑ there's all these terminologies, all this information, so... as an audiologist, basically empower them and assist these families in, like... allow them the time to accept and realize what the diagnosis means. So... it's really our job, is to tell them what the options are and do make the right referrals to different medical professionals, making sure we have a collaboration of pediatricians with the ENTs, making referrals to EI services to get physical therapy, whatever they need.

So... the thing we really need to address is the lack of professional qualifications in the early intervention process, because... there are a lot of audiologists and there's big disconnects when the baby is identified in the hospital, where the reflect is made to you and a lot of times, these referrals are sent to audiologists who only work with adults. They don't have the training or understanding of doing ABIs correctly. These children are not lost to follow‑up or misdiagnosed in the system.

So... really... there's a big gap in the care, it's almost like a vacuum of resources, like a lack of care, in many different regions, meaning like... there's not many support of Pediatric audiologists. People would speak language background, work with deaf and hard of hearing children, working with these families and so on.

So... a lot of it is suburban. New York City, within the boroughs, they don't have the resources to get where they need to go. The big thing is the continuation of care, making a bigger collaboration, to make up for that missing gap for this intervention to really happen and... for everything to ‑‑ for the continuing [indiscernible]. Mainly as a deaf Pediatric audiologist, my main concern, I want these children identified in a timely manner and making these families feel empowered and be able to accept the diagnosis and be able to move forward quickly.

This is like, basically an emergency in many levels. This child cannot communicate with ‑‑ they can't hear ‑‑ they don't know what the ‑‑ they're not able to relay, but they want to tell other peers and family members ‑‑ and want to get that message back to people. We need to be able to really move things forward.

>> Robert: This is one of my favorite pictures of five‑generations deaf twins. The mother married a hearing guy, had two hearing kids, got divorced, the deaf guy had three deaf kids and these are two with them and they're just very close to my heart.

So... primary care providers, so... we have recommended practice from the AAP, in terms of EHDI guidelines, and we're working on educating each other through our network of chapter champions to approve awareness and what we're supposed to be doing as primary care doctors, following the newborn visits, essentially.

What we tend to do, we pass on that responsibility, usually to [indiscernible] for the audiologists, as deaf professionals, we're kind of advocating for what we could do better and one of the things I'll advocate for here is to at least have some kind of a narrative as a pediatrician to be able to have that conversation about, or listen to where the parents are. To be able to refer them to the right areas and resources in your region, okay?

We often cite time constraints. I don't have time to talk about this. It's important for pediatricians to be aware of the 1:3:6 guideline and make sure our patients are following up the medical cultures, you know... like we talked about this in our physician meetings here at EHDI. I didn't order the screening tests ‑‑ there's not really my responsibility to follow‑up.

So... that's hard for me to hear because... the medical home model is entirely against that. That you as the primary care provider have the responsibility for being up with all the tests that have been ordered. The cardiovascular's dream and the newborn hearing screens. All primary care providers have the responsibility to check off that box.

So... we have that shared accountability, I'm just trying to run through this because of time. So... we are a steward of child development and primary Pediatrics, we have to either measure, listen or... enhance a parent's knowledge of their child's newfound condition which they know very little about. We have to play a rule in reducing the lost to follow‑up, making sure the patient has follow‑up with the audiologist.

So... it's very important to listen to families, that maybe their only opportunity to be honest, you know, shed some tears and guide through the process.

>> And they come to early intervention. This is how the audiology visit was. That's what happens... families leave your offices and we show up and they have so many questions. It's very new to them.

So... thinking about the role of state‑wide early intervention coordination ‑‑ in theory, our job is to coordinate services for deaf and hard of hearing children. We have to collaborate with other state stakeholders and make sure everybody's doing their job. We all know that systems state‑wide, nationwide, are not always coordinated in the way we think they should be. There's not enough qualified professionals. There are many points of entry and professional view, versus family‑centered view is very, very much alive in our work today.

Some of the other challenges we see in early intervention is data tracking and lost to follow‑up. We see that in 1:3:6 all the way through.

So... I challenge other early interventionists and early intervention coordinators whenever I talk about, let's think outside the box a little bit. Let's work to develop one system in our state, that's seamless with a 1:3:6 and everybody working together for the best interest of this child and family. Let's talk about coordination ‑‑ what does that mean in our state? What's it mean in your state? And making sure the parents are there when you're making decisions about your state. Providers agencies, making sure all perspectives, they're together and deaf and hard of hearing adults, we don't see this enough. Bring them to your table ‑‑ bring us to your table. There are deaf professionals in every state. Make sure they're there when you're thinking about what your system looks like.

And most of all, focus on the family, attachment, bonding, before all else, Jessica mentioned the insure logic emergency that we're all hearing about ‑‑ it is an emergency, but before we go on to the emergency, we have to make sure the families bonding with their bands or no progress will be made at all.

Really, as we started this presentation, our focus is language, we can't get there until this happens. This is where we start. I encourage you all to feel free to slow down a little bit. Just a little bit. We don't have to hurry as much as we're all being pushed to do. If attachment doesn't happen, that family won't do what we need them to do with their baby.

Follow your child's lead. This was another quote from the father ‑‑ a decision was right and wrong and this demonstrates how complex and delicate these choices are to make and accept. The families that we work with every day, they go from audiologists to pediatrician to early interventionists, they're being told a lot of different things. We have to work together. If we don't work together, the families will be so confused and the child will be the one that suffers. As this father said... he didn't know. He made a decision. It was right in some ways and wrong in some ways. Allow for change, allow for reflection and allow for practicing. All children are different.

Okay... I'm being told we're done. As you all know, kids are different and we have to follow their lead. Allow time for families to change. Focus on those early, early interactions, interactions with daily activities, responding, touch, interaction, eye contact, all those really early, early interactions is what all three of us should be focusing on with those families. And thank you, that was quick, quick, quick. We're here, catch us out in the hall. We'd be happy to chat. Thank you.  
[applause]

"This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings."