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EDHI Conference

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In the World of Medicine: What is Ethical?

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(The captioner is standing by.)

>>TAWNY HOLMES: Hello, everyone, we're thrilled that you could join us this afternoon for an opportunity that is a fantastic look at talking with doctors and how we can collaborate with the deaf community and how the perspectives can converge. So we've had workshops, we have opportunities to then work at NAD together, and now we are coming to you with this panel. So we can start the conversation here and hopefully continue the conversation for years to come. I'm Tawny, education and policy analyst for the national association of the deaf. Do you mind taking the opportunity to talk about who you are and where you're from?

>>JULIA HECT: Hi, I'm Julia Hect and I am the chapter champion from New Mexico and I have a long history of being involved with the deaf community and I studied ASL linguistic $s at Gallaudet in 1985 and that was before I went to medical school so I have a perspective about that before I went into the medical system and was enculturated as a physician. Thank you.

>> I am Rachel St John, I have a counselling degree from Gallaudet University and I am also an interpreter and I am happy we have lots of qualified interpreters here today, when you talk about providing services. I am the director of the family focus center for deaf or hard of hearing at Dallas medical center and we do complex integration in support of families who have children identified with hearing loss, through early language access, accessing services, getting ready for school, psychosocial development, all of those good things that people need to feel successful. So the other role that I have here connected with EDHI is that I am one of the two American academy of pediatrician delegates to the joint committee on infant hearing. We had our big meeting Saturday and there is lots of movement and good stuff coming down the pike so we are honored to have this opportunity to talk with you today.

>>ROBERT NUTT: I'm Rob Nutt I am a developmental and behavioral pediatrician in North Carolina. I was identified at 3 and a half, started wearing hearing aids when I was six. Went through school with assistive listening devices, I started learning sign language in third grade and started using interpreters in the third year of medical school. So I have that side of me.

Right now I work a lot with kids with physical and developmental disabilities in a very busy clinic in North Carolina. I look forward to sharing my thoughts with you from both of those perspectives and I am also a member of the AAP Leadership Committee.

>>TAWNY HOLMES: Thank you for your introductions, we are pleased to have both of these doctors with us today, they are bilingual, they know both ASL and spoken language. Each doctor has agreed to take on one question, make a few comments and then we will move it through the panel. If we have time we will open it for one or two questions. It's difficult with a truncated time period but we will try our best.

Each of the pediatricians want to talk about what language gives to families, and the first topic and providing an interdisciplinary view so I'm going to let Dr. St. John respond to the question.

>> RACHEL ST JOHN: I am fortunate enough to work at a hospital where I am part of a multi disciplinary team and there are a lot of people involved in the process and this was a nice opportunity for me to think about why is that an advantage? Over somebody seeing maybe a solo provider in the community? When I really think about this in connection with things like talking to parents who have just learned that their baby is deaf and hard of hearing and have no idea about approaching language, statistically most of those parents are hearing and maybe this is the first time they have every encountered this, to potentially have implants. When we are approaching those critical decisions, what is the advantage of having more people involved in the mix? I came up with two broad concepts when I was thinking besides. The first is I view this more as transdisciplinary than interdisciplinary so when we think about interdisciplinary we think about different people within a same global field so when I hear interdisciplinary I think of lots of doctors or medical providers together. I view when we are supporting and working with families with deaf or hard of hearing children this is a transdisciplinary effort, this goes way beyond folks in a medical office this is an opportunity to collaborate with therapists, deaf adults, government organizations, schools, these are people I collaborate with all the time in helping families feel comfortable in navigating the system for them. That's one thing to think about, bringing in people from outside your little world of where you practice can make a big difference in terms of where families find support. I think the thing that I get into with interdisciplinary or transdisciplinary work is it's bad against protective information. So if you are thinking about a cochlear implant, about the language you are going to pursue with your child and you see one person in one field who you perceive as an expert and they tell you to do X, maybe that's all the information you get. If that person knows what they're doing, understands you as an individual, can work with you to shift those decision‑making processes, if they're not working, that's great. But if you get one person who is kinda doing their own thing, that maybe isn't current with the data, that's all you get! So I feel like my experience has been incredibly protective against if you run into that one person who for whatever reason has really kind of misguided this family there are opportunities to protect against that and rectify that and I find myself in that position all the time, families will come to me for a second opinion and say this is what this person told me and I have the opportunity to say let me share my perspective and let me show you the data that guides me in that decision making. So I view this as a robust protective mechanism against bad information, even if it's well‑intended, sometimes that's worse.

So those are my thoughts on the benefits of the interdisciplinary or transdisciplinary view and what does that look like in working with families. I would love to hear any input from Dr. Nutt or Dr. Hect on that one.

>>TAWNY HOLMES: Would you like to respond?

>>JULIA HECT: It's odd because we can't hear whether this is working or not. I support what Rachel is saying and just by the nature of how the system is set up in taking care of deaf kids it is an interdisciplinary system, there are lots of referrals and it can't be avoided even if you want to avoid it, you couldn't. And there are lots of benefits to it but I think it's important to keep in mind that that's a lot of information for families to have to process and I think speaking as a primary care pediatrician it's our role to help families navigate this. That's the concept of the medical home is that we are the coordinators of care and that's a lot of responsibility for primary care pediatricians because we don't have training in these areas and we are the gate keepers and the ones overseeing. That's employing to lead to what I'm going to talk about on this panel which has to do with where are we getting our information from. But it is very multi disciplinary and I like the idea of looking at it as beneficial.

>>ROBERT NUTT: The only thing I want to add is the term ‑‑

>> RACHEL ST JOHN: That's my hard of hearing, I'm sorry! Ignore me!

>>ROBERT NUTT: The only thing I want to add to that is the provider, the term that we use for what we are describing, the first person the parents meet and that's ‑‑ so whether building on that discussion or whether it's clarification or as Rachel mentioned the correction of that information, that's something that is crucial. One of the things I hope you leave with today is whether you are in the NICU or primary clinic you are often times the ‑‑ provider.

So I hope you can appreciate that information to provide to families.

>>TAWNY HOLMES: It's very true, I couldn't agree more with all of your statements. Let's move to the next question. We will let Dr. Hect comment on the preconceptions and misconceptions that pediatricians might see in the field.

>>JULIA HECT: So I have had the opportunity to sit in on two panels this week end and one of the things that came up was the lack of information that pediatricians are getting about data and outcomes, the general pediatricians on data and outcomes. We don't really have a best practice model for how to take care of deaf or hard of hearing children. In general in pediatricians, best practice comes from look at outcome data and not that any snapshot is necessarily engraved in stone, but it's the best information we have at the time. So we develop a best practice model, and then as more data comes in and as there is more exposure to that and experience with it, we make modifications. We learn from families, and it's ‑‑ we don't have that for deaf or hard of hearing children so that's one of my concerns about the ethical situation because I think that families, because we have this gap in our knowledge I think that families are not able to get straightforward information about what can happen with their child to these different opportunities and options they may pick. It's what the family is interested in and what the family wants and I support families making decisions for their children but I'm convinced that parents want their children to do well.

Parents want their children to have ‑‑ to meet their potential and to have good brain development and good cognitive development and what I see as an ethical concern is that we don't have a way to really look at outcomes, choices, and are children able to meet their developmental milestones and their developmental potential and if not, what why is that? I think historically a lot of times it was considered as part of being deaf. If you're deaf you're not going to have good communication and if you're deaf you're going to miss out on a lot and, yeah, well, there might be some stunting, the brain is not going to develop that well because, well, they're deaf. But Windows 10 that actually what the child experiences and is exposed to makes a big difference in how they develop.

I'm looking forward to seeing some real attention to looking at outcomes and how we can develop best practice models.

>>TAWNY HOLMES: Did you want to talk about the recent ‑‑

>>JULIA HECT: Well there is some recent research ‑‑ I'm leading the discussion in this room in the next session, and that will give me more time. I'm going to actually look at some recent studies and some of the ethical concerns I have with those studies so if anybody is interested in more in‑depth conversation about that I would say stay for the second session in this room.

>>TAWNY HOLMES: Would either of you like to comment?

>> RACHEL ST JOHN: I think there were some nice points made and one thing I always look at when I think about where are pediatricians getting their ideas? It's not just about deaf children. We live in an age of electronic information overload and the way we seek out information and look it up and we get e‑mails, list serves, blogs, pub med and then the locally clearing house picks it up and takes it viral. If it's great data that's great and if it's not great data that's not great because it goes everywhere. So how are people getting information? It's showing up in their in box and what are the ethics of mitigating damage if something went out that isn't very good. I'm guessing that Julia is struggling with this, also, and I suspect that will come up in your talk that's in this room after, too.

>>JULIA HECT: Yes.

>>TAWNY HOLMES: So Dr. Nutt will answer the third topic.

>>ROBERT NUTT: I have the Lavalier mic, so I can stand up and move. I'm going to talk about who I am, a deaf pediatrician, do you know how many of those are around the country? One. So from that perspective as well, I just want to tell you that I don't think you need to be deaf to understand what I want everybody to be able to do, okay, and that's pediatrician, that's EI providers, everybody across the board, surgeons, everybody needs to be on board for trying to do one thing and that's what I want you to understand today and that is what I do every day, focus on the child. I don't focus on the ear, I don't focus on the matrix in the brain, I don't focus on the spasticity in the lungs, that's not my job. My job as a developmental pediatrician is to focus on the child. I think that's everybody's job. When I have difficulty with is when people focus on only one part of the person. So I get passionate as we talk about in the plenary this morning, I get passionate because I'm done with that! Okay? If we're not focusing on the whole child then they end up with any office with a problem, okay e as opposed to me just having a talk with them. So I speak passionately about this because I feel like specialists are looking too much at one part. Yes it's our job as medical physicians to be good at dealing with that part, but not at the expense of not seeing how our work with that part of the child affects the whole being. Those of you who are fellows, we talk about the life span and what you do will affect that child's life. When I give a diagnosis of autism to a deaf child or not, that moment changes their whole life. So I want you to take that to heart. That's what I am most passionate about these dies and it develops more each time I come to EDHI and I hear that we just focus on the ear and that's not why we come together as an interdisciplinary group, okay, is to talk about the child. In my short time being involved in EDHI I've seen that change and I'm thrilled about it and I'm looking forward to where we are going once we figure out screening and how to follow up, we get to focus on appropriate intervention and outcome measures.

>>TAWNY HOLMES: Thank you. Thank you for sharing your passion with us, Dr. Nutt. So in closing, I hope that what we've talked about today has sparked ideas for discussion. We want to talk about the American academy of pediatricians. A lot of you are members of that academy as are the panel members. Hopefully we can see collaborations in the future. Here are a few examples. So if you look at the policy on the website, we have more information there, but this is a physician's statement on addressing early childhood and emotional behavior problems, so there is language that might be able to be changed in the future with collaboration. They have the AAP Champion program, so working with the deaf community in those ‑‑ under those auspices might help to develop better terminology and develop a perspective of the community. Also Georgia Technical University we can see them moving modules in the discussion about the deaf or hard of hearing be community. We thank you and we hope you enjoyed the presentation. Please thank them for their participation this afternoon.

Do we have time for questions? Great.

>> What time is the next talk?

>>JULIA HECT: I have to step out but I'll be back but you guys can ask questions.

>> AUDIENCE MEMBER: (Away from mic.)

>> Can we get him a mic for CART? Thank you.

>> AUDIENCE MEMBER: I have a group of physicians in my state that don't believe we should be doing hearing screening at all for newborns. They don't even advocate follow‑up, some of their concerns they shared is they think children are going to take hearing aids out so what's the point. I was wondering if there is any effort from national organizations to provide education for physicians like these and if there is anything that I can do personally that they might pay attention to.

>> RACHEL ST JOHN: So thank you for that. I think what this is grounded in is your very first statement, there is a group of physicians in my state who believe, and that's what we struggle with, my gut tells me this is from the two kids I've worked with and I'm making decisions solely off of that is where they are coming from. We have lengthy guidelines that I have been a part of creating, and what you can do is help those folks realize that those beliefs are not supported by our academy and don't result in good outcomes. We all know what happens to kids that are not exposed to language, whether it's visual or spoken, whatever it is. You can alert them to the EDHI website, it's fabulous, it has tools for providers, some of them are belief and usable. If you Google aapehdi it's the first thing that comes up. Those are accessible to pediatricians, the joint statement on hearing, we are hoping that people can go to the subtext that applies to them, talk about young kids with amplification, screening, here is the data we have in the position statement for that. Those are two good robust resources that have been vetted in terms of you can just give that to somebody and say here is where you can educate yourself.

Whether they do or not is then up to them and that's the part I think we all struggle with is the individuality of practice and you can't make somebody learn if they don't want to learn.

>>TAWNY HOLMES: One more question. Anymore questions? No? Okay, thank you, again. Thanks for being here and thank you to our panel.   
(Applause.)

(End of presentation.)

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