ROUGHLY EDITED COPY

EDHI Conference

03.19.18

4:50 ET

Only in Translation: Applications of Data into Practice

CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

www.CaptionFamily.com

\* \* \* \* \*

This 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.

\* \* \* \* \*

This 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.

\* \* \* \* \*

>> Welcome to the next presentation, Only in Translation. Applications of Data into Practice.

>> JULIA HECT: Can you hear me if I stand over here? Is it coming through here, still? No? How's that? Can you hear me? Oh, I don't have to stand here now, okay. All right, I'm not very technical. I'm Julia Hect, I'm the chapter champion for the state of New Mexico. I'm a pediatrician, I've trained as a general pediatrician. I was the medical director of the New Mexico School for the Deaf for 11 years and I was the school doctor there and while I was practicing there I saw a need for a community‑based practice so I could work directly with families and children so I set up what's called a medical home for deaf or hard of hearing children and for children from the deaf community. So let's say hearing children of deaf parents because I know ASL parents could come and bring their kids and have accessible communication with me about their child. So I practiced for 14 years and I left clinical practice and I'm involved with working with my state in the new born hearing screening program.

I'm curious how many people here are physicians. Could you raise your hand? Wow, that's a lot of physicians, okay. How many people here work in Allied medical practice like audiologists, speech language pathologists, OTs, PTs? Okay, how many are parents of a deaf or hard of hearing child, grandparent, legal guardian. Okay. And how many use ASL, American Sign Language? Okay, wow, it's a nice mix. Thank you for coming. We only have a short time and when I submitted this I wanted to get into kind of a journal club kind of thing where we look at the data but there isn't time in 25 minutes to do that so what I decided to is take a reduction model and see what we should look out for when reading the data. We did our introductions and I'm going to tell you about some categories for review and the red flags for applying what you read in the data into clinical practice. We're going to look at when studies indicate that deaf people are inferior or flawed, when there is conflict of interest in the researchers, when there is poor study design and then when poor outcomes are obscured, which I think is unethical, okay, so red flags. There's a lot of red flags in this presentation because I only have 25 minutes, and I want to make an impact. So I want to leave you with, there are some things that you should be concerned about with data. Studies show deaf individuals to have negative personality traits such as immature, less empathy or other negative traits. Studies conclude that sign language is bad for children and implants. Be wear of studies that show negative labels and character flaws. Historically deaf people are described as socially immature, morally deficient, low empathy, impulsive and ridge bid and this is in the scientific data, okay? When deaf people read scientific data they read these things about themselves and I have a long history with deaf people and when I see this I think there is something wrong with the study because I know a lot of deaf people and they don't fit this description. Presently we have more accurate ways of talking about these so‑called negative traits and we are able to identify now language deprivation syndromes, information deprivation syndrome and trauma which can be considered as sources for expressive behavior which can then be labeled as personality straits. And when I read studies that showed looking at depression in late‑deafened adults, as we get older many people have hearing loss as part of the aging process and it was talking about depression and isolation and the one group that didn't experience that were people who identified as deaf, part of the deaf community. Knowing the deaf community that doesn't surprise me at all and there are a lot of positive reasons about why being part of the deaf community would prevent someone becoming depressed and yet the researchers of that study said that this was probably due to them not having to take so long ‑‑ they've already adjusted to technology in their early years so that's why they're probably not depressed. So we don't have positive descriptions of deaf people in the literature.

Historical inaccuracies are being recycled, and you can see the studies are from 1976, 1968 and there are studies today that ascribe negative characteristics to deaf people, and in 2015 there was a study that showed that deaf people have low empathy. Another category is studies that show that sign language is harmful and I guess I would pose the question does it make sense that a language could be dangerous?

Like outside of, like, speaking it in a politically oppressive situation where, you know, if you speak that language you're going to be punished, the question is how can exposure to a language be dangerous for development? I would say when you see studies that show that sign language is harmful, I would look for conflict of interest, poor study design and ethical concerns. We had some very important ‑‑ a very important journal for us, pediatricians, which is the Journal of the American Academy of Pediatricians, published articles in 2017 and both stated that sign language was harmful for the development of deaf children so I'm going to look at this critically for a moment. Here is the main study, and this is what I received from my American Academy of Pediatricians, when Rachel was talking at the last session about information coming out and being disseminated. I got something in my in books, clicked on it and this is what I saw, use of sign language after cochlear implant may slow verbal development. So conflicts of interest, this is touchy. When there are financial ties to industry ‑‑ when the researchers receive money from cochlear implant companies and hearing aid companies we need to think about whether that is influencing the way the data is presented. And the conclusions that are being drawn. When researchers are doing research that have an ideological stance, this is an ideologically driven foundation that supports exclusive oralism. That means that they promote the prohibition of the use of sign language in the home.

So the Gear study, the principle investigator is Laurie Eisenberg at USC family development center and she stated in the disclosure in the article that she receives funding from Advanced Bionics, but she didn't state that the family center where she works is funded by the Oberkotter Foundation and you have to go looking on their website to find out that they fund her ‑‑ where she works.

Carl, who we all know, I invited him to come to this talk, I don't know if he's here. He authored a companion piece in that issue of, Pediatricians, opportunities and shared decision making to help children who are deaf to communicate. Basically in that he stated that finally Gears has ‑‑ this is the definitive study that ends the debate about sign language. We now know that sign language can be harmful to deaf children who receive cochlear implants. He stated there was no financial conflict. He stated that he might have an unconscious bias, and he stated that he has received money from the Oberkotter foundation and you will see that he and his colleagues received a grant from 2007 to 2015. Another topic is the Poor study design. How many of you are familiar with this study? How many of you went on the website on the electronic version and saw the 30 researchers who commented on this study? Raise your hand if you read the not commentary, raise your hand if you wrote commentary for this. Some of the people in this room actually are versed in analyze this gone kind of data and I'm glad you're here and maybe you can comment after. So the first thing I noticed about this study is that there was selection bias. Let me say something about this study. The data for the Gear study comes from a large data set called the child development after cochlear implant study. That data was collected quite a while ago, and the researchers, there were six centers, it was a multi center study and the researchers have been publishing lots of papers coming from the data from this large study. So the Gear study was actual one of the constituted can Is that was published recently about children who were entered into the study a long time ago.

So the outcome of these children was already known at the time that they set up their study groups. Think about what that means. Well, the CDACI study was a prospective study where families were asked to be in the study and then they were tracked and they looked at this group of kids and how they did. The Gear study said we have all this data about kids with cochlear implants, let's see how we can use the data and use statistical analysis on it so they decided how to group the subjects after they knew how the children did. So that's important. This is a study that looked at exposure of sign language, okay? Usually in scientific constituted studies where you look to see if it causes harm, you're exposed uranium, for instance, and if you have a lot of exposure you're going to have more issues. Children who were rich with ASL were excluded but children with poor access to language were studied as exposed to sign language. Then they failed to control for other variables that affect outcome. Now if you read the comments there's more ‑‑ there's a lot of other problems with this study but this is what I want to focus on because this is concrete. You don't have to know about language acquisition to understand this and I don't know that much about language acquisition but I can understand this. An ethical concern for me is that one of the studies that came from the CDACI data was a study called Barnard, done by Barnard in 2015 and they looked at children who did not achieve any linguistic benefit from their cochlear implant even after five years post implant. They had no open set recognition of language. They could not distinguish syllabic express patterns, that's a basic part of understanding spoken language. They talked about 30 kids in this situation and these children were not included in the Gear study. The Gear doesn't mention that. I had to do an investigation to figure this out. These children, 29 of them, it's believed, or all of them except one that they knew the long‑term data on, they knew that they were exposed to sign language later. The families finally said I know you're in an oral program but our kid doesn't have language and we want to start signing and they started signing. So these kids have to be considered language deprived because you could be included in this study if you got your CI less than 38 months of age. So if you were 3 and then you had no open set recognition of speech when you were 5 years post implant you were 8. That's a very long time. A long time to not have had linguistic benefit.

Let me go back for a second. Okay, so how does a study like Gears' get published without mentioning these kids? They were obscured because they put them in the "lost" category. So they never mentioned that they knew they weren't doing well, they said we didn't study them because we don't have long‑term data about them. They were lost because they left the study because they weren't benefitting from the study. So in clinical trials in medicine if people are not doing well with the treatment and they're being harmed, then you stop the study. Or you intervene and you let them get access to the treatment.

Okay, so this is a pie chart of the Gear's study as a percent of the population. There are 188 subjects in the CDACI study and the Gear's put them into no sign language exposure, short exposure to sign language which is a group that did well with their implants so they crossed over and stopped using sign language and then the long‑term exposure to sign language, 19%. But they have a 21% lost group. Now, they were lost from the CDACI study, they weren't really lost from the Gather study, they were never put into the Gear's study and they were never mentioned. So this is the line for how many of those lost to long‑term follow‑up actually were part of that Barnard group. Okay, I have five minutes left.

I'm going to show you the next slide which was ‑‑ here, let me just ‑‑ this one.

This is the 425 children who were screened to be a part of the CDACI study and you can see that there is a group that declined. It's a prospective study and the parents said we don't want to be part of the study but when you look at the data, it was already collected and the outcomes were known so no one declined being in the Gather study because it was just numbers that was in this study.

When you look at the 425 comers to these six centers and you look at these are the Gear's people, the no short and long is the% of the Gear's study of all comers, you can see those outcomes even though I don't think it's good data, it's still a small percentage of deaf kids who came to these centers. The question is how generalizable is that data?

So in summary, I would ask you to think about these things when reading data about deaf or hard of hearing children. When you see studies where deaf people are labeled as inferior or flawed, when you see that sign language is harmful to deaf children, when there is no discussion of technology failure and children who don't benefit from the technology and when there is hidden ideological agendas and financing. Thank you.   
(Applause.)

Do we have time for questions? Okay, Rachel?

>> AUDIENCE MEMBER: So thank you for doing the impossible in 25 minutes. Awesome to just sort of see somebody take it apart and it's also really wonderful to see somebody who got things ‑‑ I pulled certain things out of it and to hear other people's perspectives and they caught some of the things I didn't clue into so I think this kind of talk is really important. I think one thing that may be helpful for the audience is that those groups that were involved in the Gather studies, the no exposure, short exposure and long exposure, those were based on parental self‑report of any visual communication used in the home so we have no idea what that meant when a parent said we use some sign, ASL, C, Q, gesture, we have no idea. We have no idea ‑‑ they defined these things but they were all self‑reported from parents so there was no investigator definition of what those categories were so you get into levels of what does this actually mean in terms of what Julia mentioned which is generalize ability to our population. Thank you for taking something complex and making it accessible ‑‑ we drown in it and I feel like I got so much out of your talk so thank you very much.

>> JULIA HECT: Anybody else?

>> AUDIENCE MEMBER: In the first half of your presentation you mentioned the outcomes data for best practices. Where is that information? Where can it be found? How can we get that information to share it with families?

>> JULIA HECT: There is no real ‑‑ that's what I'm talking about, like, this study, Gear's is considered outcomes. And say it was sent to all American Academy of pediatricians.

>> AUDIENCE MEMBER: I would hope that you can help create something to put out there, something that could be reviewed, something that we have in place that could be disseminated or put in place ‑‑

>> JULIA HECT: I hope that we will. It's not a one‑person job. Michelle?

>> AUDIENCE MEMBER: Thank you, Julia, to be honesty almost started to cry. To see some people and understanding the viewpoints of where people are coming from with this type of research, also in addition to the information that's lacking. There is no ASL assessment in this. So you can't really verify that ASL is harming the children if you're not measuring ASL use in the first place. So thank you for pointing that out. And secondly, earlier you were talking about best practices and the lack of information. We have data that shows a strong correlation between American Sign Language and the parents using sign language at home and correlating with academic and social and emotional skills. We have the data! That's what we need to be disseminating.

>> AUDIENCE MEMBER: What is AAP doing about this article, having bad data published in a journal? Are they doing anything to address the harm that's happening through the dissemination of this information?

>> JULIA HECT: I'm not a representative of the AAP but I don't know of anything that's being done. Rachel, do you know of anything? Is anyone here from the AAP that could speak to that?

>> AUDIENCE MEMBER: What it gets to is what in the publications department of the AAP what are the ‑‑ there are many studies that get published in pediatricians, this being one of them that people have problems with the study design or the outcomes of the methods. If you never had that you would never have letters to the editor which combat all that. And this happens not just in pediatricians, it happens in every journal, obviously so the question is what can journals do to combat this. I think part of the problem with this is the reviewers for pediatricians are much better versed in many other areas than in evaluating ASL or anything related to deafness or hard of hearing so that frankly when I read articles in pediatricians that are related to this topic I think you have to read them with a grain of salt because the review process it goes through is not nearly as rigorous as you may get in a journal that's dedicated solely to deafness or hard of hearing. I think when you get a journal where everybody article that's published has these flaws, now you have a problem with that journal. I do think the journal ‑‑ knowing that people do work within publications within the AAP, I do think that when they get feedback on various articles they do look at those and make decisions and get back to the authorize and I think relook at their review process. What's going to happen specifically with this would probably be nothing but I think the more you get the more there is internal process that will address that.

>> JULIA HECT: Thank you for that and the other issue is ‑‑ and why I gave this talk ‑‑ is we have to know how to scrutinize the data. We learn certain things in medical school and residency about how to read studies, but we don't learn about, you know, the issues that I brought up here in particular so that's why I wanted to address this here because the pediatricians who come here are the ones who are particularly engaged with policy and decisions and systems that we all are here because we want to afford children and families the best outcomes. So we need to learn how to be savvy shoppers, yeah, consumers of what is in the literature.

>> AUDIENCE MEMBER: And it is a credit to people in this room, some people in this room who really took the bull by the horns and did the appropriate criticisms and got those published, like the one sitting in front of me.

>> JULIA HECT: Got the comments published, right, yeah.

>> So when we talk about what did the AAP do to respond to that? That's tough because the AAP is an enormous organization and as Windows 10 people involved in the EDHI world had no idea this was going on until it got published so there is not a lot of cross‑dialogue. Two things I would say. One, any journal is made up of reviewers who are human who are prone to error, it's the nature of the beast. It's why wake Field was retracted, the big MMR study that said the vaccine caused autism, it took 13 years to get that retracted. It took a lot of feedback from the community over time. It's not a perfect process. I will tell you on a systemic level, I can't speak to anything as a member of the AAP. I suspect I share feels with several people in this room when those things landed in my inbox but from modern medicine, and all the social media things that picked this up, sign language is harmful to children with cochlear implant. When those found their way into my inbox, I was upset and as an individual I do not speak for the academy, I had a robust conversation with the editor in Chief of pediatricians. I certainly appreciated the opportunity that they grabbed to publish all of those responses and made some of those letters to the editor but the reality is the publication got picked up and went viral and the response to that I have no idea who is access it go but I can guarantee you it's not on the level that it was disseminated in the public domain and that's what we're struggling with. Don't forget about this. In any venue that you have to make a statement to whom every you think it might be helpful to, keep talking about this. These are human beings that make errors and when they happen we need to be collaborative about addressing them and fixing them and it is not going to happen over night but Julia and Rob and other people in this room will continue to have this discussion as long as people will listen to us..

>> AUDIENCE MEMBER: I'll keep it short and sweet. I'm from another country, from Italy. Gear's article I've been hearing a lot about it from my country. I don't know if there is anything published and there needs to be a review that I can show people in my country that you need to stop using this as the letter of the law. I would love to have something that's in opposition that I can bring to my country.

>> JULIA HECT: Talk with me after.

>> AUDIENCE MEMBER: Great.

>> JULIA HECT: Thanks, everyone.

(End of presentation.)

\* \* \* \* \*

This 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.

\* \* \* \* \*