 March 19, 2024

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3/19/2024  |   2:15 PM - 2:40 PM   |  Longitudinal Follow-up of Children with Unilateral Hearing Loss in Minnesota   |  Mineral Hall B/C

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(Captions provided by a live Captioner.)

 »  Good afternoon. Welcome to the Importance of Early Intervention in Cases of Unilateral Hearing Loss.  I'm Sonia Richardson, the moderator of this and we'd like to get started with the presentation.

 »  Thank you for that.  I'm Dr. Samantha Espinal and joined by Dr. Michelle Copolla, both audiologists at the Miami Children's Hearing Program. That is a mouth full. And the presentation is co—authored by Ivette Cejas, pediatric psychologist on your team. We have no financial discloser. All right. So at the end of this discussion you will be able to identify different types of unilateral hearing loss. Talk about possible adverse effects unilateral hearing loss. And what the intervention and management options looks like for these kids.

 Let's start with what unilateral hearing loss even is, so this is described as one ear with normal hearing and the other, opposite ear of any type of hearing loss, it can be sensorineural, which is when the nerve or organ of nerve is affected and causing the hearing loss. It can be conductive hearing loss, the nerve is preserved but something in the outer ear here is causing hearing loss to occur.

 There can be a combo of these, when we think of sensorineural we categorize into two somebody groups, AA, mild to moderate hearing loss hang and limited usable hearing unilaterally, which is the term LUHU, or that is severe to profound threshold range. And importantly here, there's limited word understanding. So when we make the volume loud, the understanding of speech is not there. And conductive hearing loss cognitive, and other hearing loss anomalies.

 For our purposes here, we'll keep it simple for sensorineural and conductive. Okay. You know 1 in 3,000 births are hearing loss, but of that, 30 to 40% are unilateral, so that's a big percentage of our kids with hearing loss. Other interesting instances is Microtia, about 20% of that DD, SSD is severe hypoplasia, so that's abnormal growth of the nerve in utero, or absence or underdeveloped. And about 40% will show progressive loss throughout the hearing development. When we -- I didn't have kids with unilateral hearing loss we talk about the difficult situations they could face.

 And I'll talk quickly about hearing situations. Each ear is getting unique information from the brain, and the brain figures out where sounds are coming from. Separate that noise from the signal they're trying listen to, and when we take one of the ears away, the brain has trouble with localization, listening and noise. And listening far away. A lot of time the conversation stopped there and unilateral hearing loss, it can be misconceptualized and because they have hearing in one here, people think it impact is not as important as it can be, but there is research to show.

 We'll start at speech and language and a study looking at normal siblings compared to the unilateral hearing loss, sibling, and they were more likely to be delayed in auditory and preverbal vocalizations and also see cognitive delays.

 On average, there are lower IQ scores were of course, this is not all kids with unilateral hearing loss, but this is a prevalence compared to peers.

 Children with unilateral hearing loss, they're more likely to need to repeat a grade everybody children that are older have IEPs.

 In is also listening fatigue, when the class is noisy, that plays into the academic performance because they're just so fatigues by the end of the day. And lastly, we'll discuss psycho—emotional, compared to their peers, they are louder scores in elementary school. There are physical and neurological changes that with can happen with unilateral hearing loss.

 »  Can you hear us?  Okay. So neuroplasty is the lack of input due to hearing loss. So cross modaled reorganization is when the brain essentially outsources that part of the brain getting a lock lack of input to other sensory modalities.

 So a child with hearing loss, the part of the brain responsible for touch, pressure, may be more active than the hearing part of the brain. Now cross modal can happen with hearing loss, and there's research for lower impacted hearing losses. I'm sure audiologists in the room can attest, it's hard with the unilateral hearing loss, to get buy in, parents think the parents compensate and may not have difficulty. But as she mentioned, the re-modal is still occurring, can single sided deafness, in there is decreased function and overall cognition so we'll talk by a study completed by Sharma —— whoops sorry.

 [Laughter]

Where they looked at the case of a 9—year old girl with progressive SSD, her hearing loss began at 5 and by the time she was 9 it progressed to severe to pronounced hearing loss rack. Now this child went for a cross—system and was denied a bone reduction device, we'll spend time later discusses these, but know there are options for SSD. She was in with the add candidate, as Michelle mentioned when the profound loss, the bone wouldn't work so the study looked pre implant, and post.

 So they looked at the findings, the connection from the ear to the brain in the year without hearing loss, there was typical development, whereas with the ear with hearing lot, there was a delayed hear pathway. This child had increased listening effort and mode, and evidence of cross—modal, and more active compares to the hearing portion of the brain.

 After she got her cochlear implants, they did testing, and evidence of partial reversal of the recruitment of visual, so with the sensory part of the brain there was complete reversal of the recruitment compared to the previous studies.  So when we look at the pathways of how it was integrating up to the brain, there was increased activity in that pathway and fatigue.

 As Michelle mentioned, localization tends to be very difficult listening task, I guess I can say, and they are localization improved a lot after she got her implant. As what we is see, in unilateral hearing loss, it is effected more than what we see on the standard hearing plan and at our program we feel so passionate about your integrated approach and using things past audiologist, and the screen as all our members, amazing audiologist and students, social working team, and deaf education and making sure we're addressing all the possible effects of unilateral hearing loss, and address the child as a whole. So this is a little flow chart that kind of talks about what do we do after we identify a unilateral hearing loss? We know intervention it key but that it can vary greatly on facts, including family motivation, family goals, ideology, and reason of hearing loss, and the list goes on. So we'll go further and talk about a few options and when they are applicable.

 »  All right. So I will start us off with traditional air conduction hearing aids, a option for more moderate thresholds, the thing to consider with these hearing aids is avoiding making the signal loud and causing distortion because we could be impeding that normal—hearing ear.

 That's hard to test in infants and toddlers, but if we do, we will monitor it closely. We'll start with this 6—year old girl, loss on the right side and with a whole in the year drum. By a show of hands, who is familiar with looking at audiograms? A lot of us, but some hands are not up in. So I will orient you here to the graph, this is the audiogram across the top you have different pitches left to right. Very low pitched to very high and across this side we have different volume. Very soft volume up tomorrow and very high down below, the higher up the better the hearing, further the more hearing loss, red symbols represent that right here. So in this case you can see, and those familiar with looking at audiograms twenty in kids is considered normal and anything below is considered hearing loss, so you will see the child has essentially normal hearing loss, some pitches is slight hearing loss, her SSI was not great enough to consider a hearing aid on that side. But on the right said there is a mild conductive hearing loss.

 You might also be looking at the audiogram and thinking this is really mild, is it really impacting the child very much? But, yes. The mom was reporting language delays. Listening fatigue. Attention issues. So we decided together to try a hearing aid and see how she does. So when we test kids functionally with unilateral hearing loss, we like to mimic that listening with noise situation, we show the BKSN this is clinic, it's easier for little kids. So we start off with no hearing aid to see how she does and coming in within that moderate difficulty range.

 So the way it is scored is you get an 6.5 SNR loss, meaning we have to make this signal 6.5 louder than the background noise so she can hear clearly and tested with the hearing aid on and that improved greatly, and average SNR and negative 1 decimals, meaning that signal is a little bit louder for her to be able to perform well.

 In this case, it was successful, she loves the hearing aid and is performing really well, so a win in our case here.

 »  All right. Now with will talk about bone conduction devices; this can be surgical or not, this is on the Baha soft band.

 In the cases of conductive or mix hearing losses, the bone is to stimulate the effected hearing loss ear.

 And um, the other option that we'll talk about is rerouting.

 So these are when we use this option for cases of SSD, or that LUHU, as a rerouting. So not necessarily to restimulate that effected hearing loss ear. Instead, to send the signal over to the other ear. It's more for sound awareness and less for localization and things of that nature. Next patient here, 6—year old with right—sided microtias he is still using the BAHA because he's going over a atresia repair. The right here is moderate conductive hearing loss, and he does really well, with his Baha. This child primarily speaks Spanish, and we know for the audiologists in the room, we know there's not a lot of tests for kids, but he's pretty bright so we tried the BKSN but without the device only getting 4% words correct so not doing pretty great without the device. And then we tested with the device on and jumped up to the 73% words correct so he does really, really well, with the Baha, and note: Is it normed in Spanish, so he'll probably do better.

 »  The next is rerouting options like Michelle mentioned and they're typically recommended in our SSD or LUHU candidates that aren't candidates for cochlear, the device on the right here has got a mic that will route to the other ear. So this is another case study. We got a 12—year old girl, hearing loss secondary to Bacterial Meningitis and has unilateral hearing loss. This patient tried cross Baha and went a consistent user, so in her case unilateral hearing loss, so we decided to try again and did the testing and there wasn't necessarily a huge difference with and without her cross on. So with her cross, 2.4 DB, S and R, and that falls into the normal category, with it on there was in the same category but with the improvement. She's now a lot more motivated to wear the device because of the decline of the left year, and our next option is a cochlear implant. These are a little different, of course, than the rerouting options where this is going to directly stimulate the texted ear. Typically looking for severe to propound hearing loss, but I want to point out this instead of the amplified hearing aid, because it would be just distorted. The next patient is ten—year old, no response from right here, left ear is normal lifts and the red CIs are aided access, and definitely improvement where she was not responding with the device on and that improvement is expected for a cochlear user and with that on in the 4.2 range, with the implant on that score increases to 2 and kind of raises the category and is now in the expected range. It's important to highlight, hardware doesn't always have positive outcomes. This is a 9—year old with a long—term user and when you look at the aided access, not much improvement, and her hearing range is poor in that year. She does really well, but with it on a little bit of a difference. In her case, the family is not interested in other options, she is very motivated to autos the hearing aid, and she, she feels huge benefit, so we don't disagree because it's not causing huge detriment.

 »  Okay. As Sam just described, no device is an option, sometimes we can't quantify that function in the option, and the family isn't motivated, so sometimes not an option. And the cross—functional we talked about, sometimes is not the case, sometimes kids with unilateral hearing loss, they are fine at school, they are just more at—risk.

 So there are a few things to consider especially when we are going to no devices and starting with classroom accommodations, we have hearing assistive technology that's available. More specifically, we have ear—level hearing assistive technology, that's when a child wears a hearing—I'd like device and the teacher wears a microphone and it streams directly into the year and this takes away the distance that unilateral hearing loss, kids, sometimes struggle with and the noise. If there's educators in the room, you know how loud the classrooms can get so this is important for kids with unilateral hearing loss. This can be implemented in the sound field setting, so instead of on the child's ear, there's a speaker in the classroom to all of the kids and research shows this helps not only the kids with hearing loss, but all the kids in again. And I always emphasize strategic seating because we want to utilize their good working here for benefit and access to the classroom and their peers. So making sure they're close to the front but also that their normal—hearing ear is positioned to the rest of the classroom. Because we learn a lot from other students. Offering repetition, visual cues and note—takers can also benefit our kids with unilateral hearing loss. And another key piece is that monitoring. So even if we decide not to go with the device, we want to keep up with the audiometric care. We know kids with unilateral hearing loss, are more at risk for progression. Not only in the ear identified with hearing loss, but on the normal ears as well. So beyond that audio, we want to keep in touch with your social—emotional well—being, as you heard there are so many options for kids with unilateral hearing loss. So many causes and approaches and it's not one—size fits all and we do try different things along the way. What we do know is early diagnosis, early intervention if that's the route we want to go and monitoring are all things that help kids are unilateral hearing loss, to help them succeed.

 »  These are our references thank you so much.

» The QR code on the screen is for Instagram, fun events and knowledge and stuff. The QR code on the right is our program and we're actually hiring, thank you for listening, I'm not sure if you have time for questions, moderator?

 »  No, you do not.

 »  Find us later if you have questions or anything.

 »  Thank you.

 »  Thank you.

[Applause]

» Good afternoon. I think we're going to go ahead and get start, I'm Sonia Richardson, the moderator and I do think we'll have time for yes at the end, so I'll pass around the microphone so welcome to longitudinal follow—up of unilateral hearing loss, children in Minnesota.

 »  Hello, everything, my name is Darcia Dierking and I'm a pediatric audiologist for almost 25 years and for the last ten years almost, a public health audiologist, so I know this presentation will be interesting to audiologist probably and people interested in public health follow—up. So I had a slight freak out with we might not make anybody up or make people slightly happy.

 If you were coming to this presentation with a particular graph, or slide or analysis, we want to hear about that. Because there's probably a hundred different ways, we would have presented this data, so if you have anything to write down and send us after we would welcome that. So we're going to talk about longitudinal follow—up for unilateral hearing loss, in Minnesota and I want to thank the previous presentation because they outlined a lot of what we'll be talking about.  We had a law in 2007 adding hearing screening panel and identified advisory and identified hard of hearing and deaf adults as strategic partners in the EHDI system. Minnesota does provide short—term and longitudinal EHDI programs and the law defines children all the way up to adulthood, so we do ask audiologists to provide to the age ten, meaning up to the 11th birthday and we'll track it after that. Minnesota EHDI tracks with, and we get data on our own, but we do rely on education partners for a lot of outcome data. We also participate in the Early Childhood Longitudinal System in Minnesota which includes kindergarten to third grade outcomes and I'll talk more about that in a second.

 Minnesota has close to 300 reported cases of permanent, confirmed hearing loss in 2023. And so this includes both congenital and late onset hearing loss and have reported more late in the last four years. I used to tell me we had 250 case I year and 160 from newborn and another 50 late onsets, and now we have another 50 late onset probably.

 On average, a third of the children reported to the Minnesota EHDI program, which includes both congenital and late onset initially identified with a unilateral hearing loss. So that would be the blue bars at the bottom across many years that we have been tracking this. Bilateral screen and very top, a few little red cases that are unknown. But those cases are permanent hearing losses that just have testing still in process.

 All right. Now I'm going to put on my public health hat and talk about follow—up. You all on about the joint committee on infant hearing and the recommendations of medical specialties, including ENG and ophthalmology and part of public follow—up is looking to see to do program evaluation to know what are the uptake in the population of these recommendations.

 And so, um, we know that nearly 90% of children are evaluated by ENT, and close to 40% for genetics and ophthalmology and this little gray and black graph is actually from 2014 and that was collected by primary care providers and whether they were evaluated by the specialty care providers so we provide just in time information to primary care providers by sending them a fax. I know, very antiquated but it talks about the joint committee recommendations and ask them to prompt evaluations.

 We also know by talking to their ENT community that they are also making these referrals as well. So we depend on many, many providers and audiologist as well, to talk about these recommendations.

 So, um, when we were doing follow—up to find out about this graph here, we were primarily doing it with fax backs forms and phone calls.

 [Laughter]

Which took a lot of time. Probably twenty hours a week and was often incomplete and lastly before I turn it to our colleague, our epidemiologist, I want to talk about academic achievement. Because that is one of the things we can get through our educational partners with the Minnesota longitudinal data system. This is a secure system that education puts information it, EHDI puts information in, the Department of Human services puts information in, and you can filter from your cohorts so we put in unilateral, and they put in grade level achievement. And soon to be putting in some language acquisition data. We do put degree and laterality of hearing loss in, in but that is initial at the time of identification. And so sometimes that isn't

up—to—date by the time they take a standardized test in third grade so this project aims to help with that data using health records abstraction.

 This is just one example of information that we can get out of the early child longitudinal system, this is reading proficiency scores in third great, one set is pre—pandemic and post, pre—pandemic, is the blue bars. For unilateral, it does follow pretty much the proficiency for all deaf and hard of hearing children.

 And if we were to filter out the children that are, am, not served in special education as a proxy for knowing if they have other, one um, conditions that they might be served by IEPS, if we were to filter them out, they are generally performing close to that you third—grade children cohort. And I will pass it to Sara.

 »  Sara: As she said, I'm our EHDI epidemiologist for the Minnesota Department of Health and so I'm going to talk about the abstraction process and longitudinal follow—up for children with unilateral hearing loss. So in the summer of 2020 we began this process to better under the approximately 300 children with unilateral hearing loss. We are lucky in Minnesota we have electronic health access for hospitals covering more than 70% of births and because we were interested in third grade academic achievement, we wanted that age range of 7 to 10 to better understand and match with the Minnesota of education data, so better present that data. So we abstracted information on sedation decision—making, and timeliness of use, ENT, genetics as well, as ideology of hearing loss, if those were previously unknown. So I will go through the abstraction process, first children born between July 2012 to July 2016, with unilateral hearing loss. Our lovely colleague scheduled the EHDI system and served for the hospital systems with access. She then updated any new information into our EHDI system, Darcia checked each case and if needed with new information, she sent that case back to the abstractor for further investigation.

 This is what we found, initially 319 children with unilateral hearing loss, currently between the ages of 7 and ten years old. 8 children were ruled out, 7 cases moved out of state and one child it died. So we were left with a cohort of 303 children with unilateral hearing loss, currently with the ages of 7 and ten. Of those currently, 7% were children we they were saw in places without long health access, 9 children unable to find information, 43 found new information but no updated audiogram but for the majority of the children in our cohort, we were able to find updated information with at minimum a new audiogram within the past 3 years. So next, we wanted to understand the unilateral hearing loss, and some of the 163 bench marks and specifically because we do longitudinal follow—up, which is after diagnosis, we were specifically interested in 3 months of age and referral to early intervention by 6 months of age, of the 303 children with unilateral hearing loss, approximately 70% of those children were identified with congenital hearing loss and have those, approximately 3 quarters were dice nosed with that hearing loss within 3 months of age.

 This slide shows our late onset, children with unilateral hearing loss. And about 3% were identified with either late be onset, or unknown onset. As you can see as well, more than 75% of children with unilateral hearing loss, that were diagnosed late onset were diagnosed after the age of 5.

 And there were about 80 children who were categorized as late onset. Secondly, we wanted to look at enrollment and timely enrollment in part C.

 So nearly three quarters of the children in our congenital unilateral hearing loss cohort, were enrolled in part C. As you can see on the figure on the right, approximately 60% of those who were enrolled, not all of children, so those that were enrolled, 60% were enrolled within 6 months of age. Similarly, as you can see, there's a trend over time. So the ten—year olds would have been around the year of 2013, the 7—year olds around 2017 we are improving our timeliness of enrollment, whereas with the 7—year olds, about 75% were enrolled within six—months. We also were interested in referral and evaluations for ENT, genetics and ophthalmology so more than 70% of our total unilateral cohort were evaluated by ENT, you can see 94 of the late onset. Among those who were evaluated, 66% of those who were diagnosed in the congenital time heard, those were evaluated within 4 months of birth and among our late onset kids, 65% of them were evaluated within 4 months of diagnosis. So we think we're doing pretty well, with being evaluated by ENT and pretty well, with your timeliness of our referrals.

 Unlike the ENT, only about 50% of the children with congenital unilateral hearing loss, they were evaluated by genetics of those that were evaluated, three quarters of them were evaluated, those with late onset, only a quarter were evaluated by genetics of those that were evaluated, about 37% were evaluated within the year.

 And then lastly, we wanted to look at evaluation and referral. Um, to ophthalmology. Um, and so about 50% of our congenital children with unilateral hearing loss, were evaluated by ophthalmology and about half of those were evaluated within 6 months of births and slightly less among our late onset cohort. And about 45% of those were evaluated within six—months of diagnosis.

 And so overall, um, Darcia presented this graph earlier. As you can see, a lot of our referral rates and evaluation rates, by ENT, genetics and ophthalmology have remained consistent over time, these are cross—sectional evaluation during the time periods, so we don't necessarily know what happened in between, but comparing the two, they are pretty stable and consistent over time. In addition to referrals by ENT, genetics and ophthalmology, we were also interested in understanding family's choices for hearing technology, as well, as timing for hearing technology for the children with unilateral hearing loss. So on the left, you can see that approximately 50% of our cohort were hit with hearing technology. And on the right, is a subsection of the children who initially decide, or initially did not get fit with technology. So among those, who initially waited, declined, or their families declined, more than a third of those families eventually chose to fit with hearing technology over time. We also were interested in the timing of hearing technology for these children. And so the figure on the left indicates the year of age before birth and permanent diagnosis in blue.

 And then in green is the amount of time between permanent diagnosis to initial hearing technology fitting. So as we previously showed, the children with late onset hearing loss are diagnosed around that 5—years of age, but they are fit with technology about less than a year after, um, they are initially diagnosed, so smaller timeframe and that's typically around the time kindergarten. And below that, the children with congenital unilateral hearing loss, and their families usually approximately a year after diagnosis on average. So over time the age of diagnosis and age of initial fitting has gotten younger over time. And on the right, severe hearing loss that chose to be fitted with technology, more than 50% of children with congenital unilateral hearing loss, over 50% chose technology for their child. This one shows more than 65% of families chose hearing aids, about a quarter chose bone conductive hearing aids and less than 10% chose cochlear implants. One of the last things we wanted to collect was etiology, so the most common etiologies were structural, including enlarged aqueduct and genetics were another, as well, as in vitro, and we did fine some, and extracted those, 88% of the in utero infection were CMV. So after collecting all the data, we wanted to see is your children matching with the matching with the Minnesota education Sam, and making sure it was matching systems, so we did have 29 children through the act traction, had progresses from unilateral to bilateral, so about 10 percent of your cohort so we can now do the EDLS match to see the language acquisition outcomes, as well, as educational outcomes for those cheaper. So a little bit about the abstraction process. Although we were able to find and update information for cheaper with unilateral hearing loss, in Minnesota there are still challenges to abstraction and data completeness. Like we said, some children we have no access to, and we need to find updated information for the children, we could need to fax or call the clinics that don't have the electronic systems and we found the longitudinal took 80% less time and was more secure than calling or faxing the clinics and also results in much more higher—quality data and more complete data. We estimated on average, electronic abstraction look less than ten minutes for the cases, so Vanessa pulled this information while abstracting the data, so lucky for her, she only had to look at one facility for a lot of the information. For someone reason, the next highest one was three clinics, we don't know why that's the case but a quarter of them had to look at three, and thankfully I did want have to look at more than four clinics. So lastly, we want to look at ways to make this abstraction process was successful, first we have successful abstractors are key. We're lucky to have Vanessa and there needs to be clear job guidelines and clear determinations of the type of evidence need in order for that to be documented. You also have to be flexibility and time to press the process, as we state we started this in the summer of 2023 and it takes time to abstraction of the data, we're all working on other things as well.

 [Laughter]

And lastly, we need to have data systems in place to collect and store the information we're lucky we already had our EHDI system in place, so we didn't have to build this.

 And so, what are our next steps? First we want to increase the efficiency, so we, we know kids are seeing ENT by a certain age, we can abstract that data at that timeframe instead of year after year, and also want to reanalyze the EC ES data for education, which will be later in 2024 and lastly we want to update our parent terms about unilateral hearing loss, with family—friendly state—wide data well, as targeted recommendations aiming to increase the uptake of JCIH guidance. And thank you for taking the time to listen to us, I don't know if we have time for questions, but?

 »  We do have time for questions, if anybody has any questions?

[Off mic question].

 »  Hold on one second. Sorry.  There's the microphone.

 »  If you are going to continue, or can continue to follow these particular, you know, cases? And then also, I figured I'd make the comment that it would be interesting to see, because you know, I'm not surprised to see how many people who is hearing aids as their device option, because they were not FDA approved for single—sided deafness in while until recently, so I'm wondering if that will change through time as well?

 »  I'll answer that question. I think that, yes. We are also performing these abstractions just in general for our, um, younger babies. And so we will have that data. But we don't have complete data yet to present. Um, but yeah.

 That's just part of our longitudinal follow—up in general. We just wanted to make sure we had our updated, um, some updates for our older kids since we're matching on third grade outcomes.

 »  Any other questions? It looks like you guys are well spent, thank you so much for coming to our presentation. I hope you have a great break. Thank you.

[Applause].

[Applause].

[Break was had.]

»  Okay. I think we're going to go ahead and get started and at the end, they're hoping to have five minutes for questions, so this is thoughtful family engagement by Tawny Holmes Hlibok.

 »  Hello, everyone. Good afternoon. We are so excited to have everyone here. I know we're kind of going to be in a time crunch, so my name is Genie Gertz, and this is Tawny Holmes Hlibok and we had another writer to recognize, Melissa Herzi we wanted to recognize her but she's not with us today. You can think about this in a lot of ways: Thoughtful family engagement.

 So the focus of this presentation today, we just want to recognize that this is a process for families. Coming to the realization that they have a deaf child. It's not a simplistic process, it's complicated. Not for any negative reason, just new. Comes with a lot of new thought processes, a lot of questions, and maybe mixed emotions. And we have to recognize that in these family's journeys.

 So we also have to recognize that there's a system in place that sometimes opposed us. Sometimes presents us with barriers and challenges, and so we'll address that too.

 But the intent of this, is that we want the family to be completely engaged and supported through every part of the process. Because this is a new world that they're entering into. A totally new environment, and they're going to have questions. They're going to need help along the way.

 The biggest barrier we see ——

 »  Just and I think maybe just being able to ——

 »  So language. Right? I'm trying to think how to introduce this. So I want to tell you that I'm a professional. I am a professor of deaf studies at Gallaudet University. Both of us are. I have been in this profession a long time, been through it all, published, et cetera, at the same time, I became a mother to a deaf child. So when that happened, it wasn't exactly new. But it really was a different lens. That I was seeing the world through. And so I have what I know, and all of my research and everything that I have experienced and all of the sudden I was handed this totally new experience.

 And in that, I saw challenges. And I saw barriers. And I experienced the system in a way that I had not experienced it before.

 »  And it's very important to recognize that the intersection, the intersectionality, as an attorney, with IEPs, myself as a professor. I have four beautiful god children, the oldest is going to be 21, and the youngest is 12. So we have seen this from all the perspectives. All of the different views and modes that you can see it from.

 And what we want to do is to be able to set up a framework for you to understand.

 Um, with the research that we've done and what we've worked with, we wanted to be able to show you this.

 »  And we'll show that at the end.

 »  Yes. And that led us here, with your perspectives. With your experiences to be able to speak with you today.

 So that chapter that we're going to shot reference for at the end of the our presentation, when we looked into that, and then examining the system, we're acting as professionals. We're supporting that system.

 And supporting that existing framework. But then also, the parental experience. We're seeing it and experiencing it in a different way. And so just that context of choice. The choices that are offered to you. As a parent are not always the same across the board.

 Um, I'll give you an example. Like what... You know, there might be something that might work best for you.

 But at the same time, there are choices still available.

 And so when they're viewed in the context of one being better than another, that can prioritize them unfairly. There's also going to be challenges that are going to be met along the way. Let's talk about informed decisions. So how are decisions made? What kind of information has been passed to you? It's not all equitable and it's not all transparent. Sometimes the information that's being given to you is biased and skewed. The person has an agenda. And then you go talk to someone else, they have a bias and agenda and they're recommending something different to you, so you need all information presented to you, unbiased.

 »  So I have experience. I have bias, I was on a panel this morning. There was one example that was given about gene therapy, whatever that whole thing was. Um, so how are the professionals who are involved in that genetic therapy, whatever you want to call it, right? They're presenting their information, their research, but they have their own biases. And then apart from that, there's going to be other professionals presenting a completely different perspective based on their biases and they have to have acknowledge the impact. So as a professional, I don't have adverse consequence, as a professional I don't want to cause deprivation, but it's possible so it's important that kind of power is recognized.

 »  So the deaf parents are trying figure out what they're doing, you know? Maybe they see another parent who has a two—year old that can sign better than their 4—year old; and they want to know why so it's important to have authentic, transparent engagement from the family, everyone involved, all stakeholder and especially the child.

 »  And as we mentioned, being able to provide a framework is so important to what you are considering doing. What you talk with the family, when you are providing services, the family decisions that are going to be made, or have been made, it's... A matter of how you're going to proceed with that. Language acquisition and the framework that you use for that, how will that work? How does that go on? How is that used? You're going to want to talk about, um, the choices, and accommodations and variety of languages and modes and what can be used and what are the options, if we're talking about early intervention, what we're going to do at that point, the technologies out there, you need to talk about the aspects, and we all know the exposure to early language, that is not a question. Obviously, there's miscommunications, like we just talked about. Gene therapy that was just talked about, that's not a cure. It may give you the

5 decibel of hearing, but it's not a magic bullet that solves it, so there's needs to be communication and any misunderstanding, the professionals need to be involved to help the parents understand. When we're talking about language development, what approaches are we going to use? What's possible? What's viable. In we're going to use bilingualism, what are we going to do? Mostly signing, and add speech? Or the opposite? It's the matter of being on the same page, to making sure that the families are moving and progressing through their journey as they're experiencing it.

 The visual phenology when you are talking about that, what are the limitations? We need to make sure we're emphasizing there is one way to learn audioically, but also finger spelling, graphs, speeches, languages, whatever we can do to provide communication and make sure it's beneficiary to the child and the parents especially. Quite often you’re presented with an either—or scenario. You can have this.

 You can have that. It's always black and white.

 One way or another.

 But as a deaf parent of a deaf child, I was able to get early intervention services and I got through those properties, I thought what's wrong with doing it all?

 [Laughter]

Isn't that the point?

 »  Being inclusive.

 »  This is a whole person, my child, give them everything, thinking about language for example, everything else just becomes skill—based and there's nothing wrong with adding onto that.

 But presenting things as you have to either go this route or that route. You're either going to access this or that, is really limiting. We're talking about total communication. Bilingualism, there's nothing wrong with that.

 There’re some deaf kids that might have more access to spoken language than other deaf children and that's fine. There's nothing wrong with that.

 Like my daughter for example, there's, you know, she's fluent in sign language.

 But she always used spoken language, she also enjoys hearing things. So it's, it's the way that it's presented. The way that it's framed. Either—or, like these two things are opposed to one another when in fact, they can be complimentary.

 »  Because we have research, we have the material out there that says at ASL or signing is a barrier to be able to learn to speak. That is debunked so many times. Learning is learning.

 And using sign language, can you learn speech just as well, because you're using sign language. Research has shown that the two of them together is not just one. And a child can learn to speak, just speak and that's fine. And research shows that, that if that the, the goal family and they're provided tools and resources, that's fabulous. But if you add sign language and integrate that, that allows more access. Again, going back to not this or that. We're not talking about one or the other, we're talking about both. From the time my daughter was maybe two or three, her morphs were right on the money. Not that I know I taught her, they had a knack for language and picked it up naturally.

 »  And 30 years of early intervention and right now the paradigm is this: The impact. Just in the fall we had four states, California, Kansas, Oregon, Montana who approved the lead K. 70 to a hundred percent are not meeting their language acquisition milestones.

 70 to a 100% are not meeting them, those are the numbers from those states. Montana is a hundred percent, they have gathered the data and seen what's going on with children 0 to 5 and they are not meeting their milestones. And that is proof. That is strong research that proves that there is something missing. That a deaf child can be effective. They don't need to be delayed. They don't need language deprivation if they're providing the language access and the tools. And sometimes when you say we just have to use one approach. That's it. That's a Hendren CP. From the center of deaf equity, it shows the deaf child's experience with language, a deaf child with impact them with health risks, cancer, ulcers because of their experiences as a a child not having I language, so there's a loath of future pain being caused for that child because they don't have that access.

 Also, the social—emotional community, the research to that, the access to that, you know, understanding that it's okay to be deaf. You know? I remember during law school I saw one person that had a cochlear implant, and I was thrilled because I'm not the only person in the room that was deaf. And I said hi, how are you they said I'm not deaf, I don't sign I said it's okay, we'll text, and they said I'm not deaf, not deaf. Okay? Okay. So what's your name? Would not even engage, I can't talk to you, and they left. And I thought, you're like me. You've human, I'm human, we could have had a connection. And that happened not that one time, but other times in my life and being able to have an identity, and being able to understand who you are. Because if we think about your deaf children, it's not just one aspect of the population that is deaf. We have a variety of children, we have BIPOC, all of the children. Children are children, it's not just one specific social socio—economic group.

 »  To pick up where she left off, what are the cultural and ethical considerations here? Quite often as a provider we have to check in with privilege. How are we presenting things? Like she was talking about diversity. If I see myself different from them, how do I navigate providing services for someone I might have a bias against? What are their cultural considerations? What is going to lead them to the choices they're going to make? Their choices are going to be guided much by their culture.

 So diverse cultural identity, sometimes it's not one identity. They exist in multiple, different worlds. And so I have to, I have to figure out what, and how do I present myself to the world? How do I identify? And if I understand where I'm coming from, then I can understand how better to approach the people that I'm serving. But again, it just goes back: Check your privilege. We want to cause no harm. Harm can sometimes be unintentional.

 And so you can't eliminate harm.

 Certainly, there's going to be some unintentional, but we can minimize it. We can prevent compounding harm.

 But that all depends on checking your privilege, where are we coming from? What are we presenting? We hear stories from families that are lost along the way. The information that they're getting from professionals. What they're getting from their doctor. And it really just makes them retreat from services. So we really want to minimize that and have them access as much support as we can give them.

 Language can't hurt anyone, language never hurt anyone at any time, so the whole language approach. So by recognizing that, we can then empower families. We can raise them up and what ends up happening is connection to identities. That gives them confidence. And a holistic approach to supporting this child.

 »  I know that sometimes we think, okay what are we doing? As an attorney, I think about law, of course, and I think about policies. And I think about how can we switch paradigms? How can we open minds? How can we do something legally to change things? But one of the things we cannot, or we neglect doing is remembering the language acquisition is there. From 0 to 5, a child needs to have language. Because that deprivation is going to happen at that time, we need to make sure the child understands what's going on and if they're able to understand one, that's great. What happens when they're at the dinner table, or out with friends or at a party and just not one—on—one with someone? We need to check in with them and make sure they are having access to language, with providing interpreters? Services? What are we going to make sure they are engaged and still part of it? We need to make sure that the language we're offering them is language that they will use. You know, if we say okay, you're going to have this next week. And you're going to do this, this week, we make sure the schedule is in. But we make sure it's all included. We make sure we're giving them what we can. And we guide the families, you know, knowing or own bias and our own background, learning their family's culture and language, bring that to the table while you're discussing it and invest in the early learning program. Not just services, but the holistic approach, make sure they're with their peers, educators and other individuals. We need to make sure that's all happening. And we need to make sure the child is getting through the system. Because what we want is for them to be able to succeed wherever they are.

 »  I think this part's kind of self—explanatory. What should happen. We kind of already touched on all of these. It's important we expand family connections and also make sure that cultural competency is included in our trainings. We don't expect them to match our culture, in fact, we want to meet them where they are. And also trying to get more diverse professional recruitment. We want people that don't look like us. People that aren't the same as us. We want to be as diverse a force as we can be. And again, reframing language choices. It's not this or that. We want to make sure that we're providing all options to them and then giving them the autonomy as they see fit. And also, more deaf mentors, there's some but we need more out there. This is the chapter, if you want to read more into it, you can. Those are our references if you would like to take a picture.

» I think we have time maybe for one or two comments? Are there any questions? Comments? No? Okay?

 »  Thank you.

 »  Thank you.

 »  Thank you, thank you, thank you.

 »  Thank you for being here. Thanks.

[Applause].

[Applause].

 [Laughter]

 »  Test, test. Captioning test. Okay. I think we're going to go ahead get started. This is What's New in Education Law.

 Good afternoon, whoever was not here the last workshop, my name is Tawny Holmes Hlibok. My name sign is Tawny.

Chris Payne—Tsoupros, nice to meet you all. Let me explain our role. What we're doing here. We're going to talk will legal laws for the deaf individuals. My co—presenter here we both talked —— blah, the interpreter had a mess up. One second.

 We both work at Gallaudet university, focusing on deaf studies with including sign language, rights, legal rights, language analysis and the director of the organization that's called CESAD, conference of educators, for schools for the deaf, it's the oldest organization in the United States so I'm so proud and honored that I'm there, and that's in the United States. Over to you?

 »  I left Gallaudet. And I am now, —— there are a lot of big shoes that had to be filled when I was trying to figure out what I was doing.

 And walking into Tawny's shoes, it was very difficult to make sure I was filling those shoes. But I teach part—time with a deaf ten-year-old and hearing 9—year old, just 9 recently, I'm going to switch to voice now and let the interpreter sign for me and back to you, Tawny. Do we have a microphone?

 »  There it is.

 »  Is it on?

 »  Yes.

 »  Perfect. So here is our plan for today. So introductions. Checked. We'll go over our agenda for our remaining 22 minutes that we have together. We'll do a brief overview of laws to know. So we're talking about ADA. Americans with Disabilities Act, 504, connection 504 of the rehabilitation and talk about the Cogswell and Macy so it's great to have a light and not technical presentation to close out conference.

 »  Right.

» So when you leave today, here's what we want to you leave with. So be aware of the new bills. And the current status of the cases with the Supreme Court related to deaf children. Resources. Additional resources beyond these 25 minutes, that you have together.

 To find resources relevant to the ADA, 504, IDEA and recognize specific provisions to deaf children so when we say deaf children, the big tent, deaf, deaf blind, hard of hearing. All those kiddos under the umbrella of deaf.

 »  Okay. Just to let you know, this will be very visual, a lot going on. Not strobes or anything like that, but there's a lot on the screen what I want to show you is the differences with the laws we just talked about, and I want to give a small snapshot of those.

 I have a chart that will show you each of these individual components. Understand, that a law reasons it's passed legislature, passed Congress, it's a United States agency that is going oh, oversee the laws, that they are followed, provided, that they are going to be in.

 Especially education law, there's overlap. It cannot contradict federal law, it can be more so but minimally has to follow federal law. I've give you a minute to look at this quickly.  A lot of people are taking pictures so that's great. As you can see, the ages in the law could be very different. Birth to 21 years old. 504, it precludes —— it's a precursor on the ADA, and that's any age, so it talks about how do you get services? How do you get the protect actions of the laws? With the i—d—e—a you must qualify, and it must impact your education so not every deaf child gets an IEP, they have to go qualifying for that. Section 504 is a disability that substantially limited their major life activities.

 Applying that law to everyone.

 It's not just to private schools. It's not just to private individuals. It is a law that is applied to everyone.

 Section 504 is federally funded. And any entity that is federally funded, must follow 504.

 ADA is anyone, any public access.

 So these laws apply to... Who and where? I—d—e—a, local, state, federal, that's the IEP, gathering information, this is interviewing, this is being able to find out what's going on.

 ADA is when requested for. If someone's struggling, you provide services to them. You make sure that they get the service they need. You know, if the family says we need to have access, then it's a two—way street to be able to get that.

 The i—d—e—a is specially for the child for education, so it's not something that you can compare to other places, other things.

 In the past when we talked about Section 504 we talked about free and accessible education. When we're talking about ADA, we're talking about reasonable accommodations.

 So it's the way it is being measured to see how the services are being provided. The Supreme Court, as we were just talking about earlier... They are setting precedent right now. And interpreting the law for the benefit of education. But that means the minimal benefit.

 It doesn't change and it will not change in a year, 504 is again, appropriate accommodations and ADA focuses on effective communication, we can't compare to another student when you were talk about i—d—e—a, with section 504, you compare it to the actions the other students are having. The ADA is compared to the other students there. The United States of justice has an 20 14 have struggling with ADA, and i—d—e—a so that means if you are having trouble with captioning, you can request an interpreter. In the past, you were asking for too much, but no it's just providing the minimal amount, it's not providing more. So now it's making sure it's not just the minimum.

 Each law is separate. And you need to supply it separately. So we need to be careful of that.

 You can have a section 504 plan. And it can be with or without the i—d—e—a. But the schools also can have only a 504 plan. And with a void having special education. So that's something you need to watch for and especially if you are talking about IEPs for your child.

 I—d—e—a and 504 are part of a plan between the schools and the parents, and the individual needs, what they are. The schools must follow the ADA, the funding is included with that.  If they're not following that, they're not complying, then there's going to be some research into what's happening. Why they are not following it, and it would jeopardize the funding they could get from the government.

 So those are things they need to keep in mind for services, as they are following those laws.

» Now we are going to take a brief tour between some Supreme Court cases, before we talk about Riley, why the i—d—e—a was first passed in 1975, at the time was called education for all handicapped children act, the corner stone of i—d—e—a is disabled children have the least restrictive environment and we know how been misinterpreted for looking at FAPE, that was the in statute, right? Free appropriate education, Amy Riley, you know? Raise your hands? She had deaf parents, somehow that piece of Amy's story has not made the story, Amy had full access at home, her parents wanted her to have an interpreter at school to access curriculum and peers, and went to the Supreme Court, she was passing grade level benchmarks, her mom was reteaching her at home, who was a deaf teacher, that was not part of the Supreme Court's analysis, they said okay, she's passing through. The i—d—e—a doesn't require more than that, so really the Riley case in 1982, FAPE required the bare minimum and that was the what was left with until 2017 when Andrew F came along.

 »  Just clarifying spelling.

 »  She was a 5th grader with autism and his parents wanted him to go to a special school that can meet his needs and get reimbursement from the local school district, and the school said no.

 The Supreme Court said okay, what's required is a smidge more, the minimal is not enough, it has for more than trivial so in someways it tried to put more see the compared to the Riley, compared to the cases is it thank substantively different? It's not the best of the kid's needs, it's accessing the curriculum. And often if they're meeting grade—level benchmarks, they're doing it. That's 2017. Most recently, the national association deaf of the involved with Miguel Perez, he was a deaf 9—year old, he's now a deaf adult, he was a 9—year old with no language, basically long story short, 9 to 20, he was just passed through with a sign language interpreter that was training by a book and just making things up and the family was Spanish, and often times interpreters were not provided for the parents, and ma angle was on the cusp of graduation, and they said you don't meet the requirements to graduate. So I can discuss that more after, if you would like, but the Supreme Court decision was actually a very narrow technical issue, the school settled and said we messed up on i—d—e—a we did not provide you the education you deserve going forward, can the family say you are responsible for the discrimination you caused our son years back. So it's a very technical issue on that point, but Supreme Court said yes, he gets the education going forward and the school is also financially liable, they have to pay for the discrimination harms for not providing proper access. What does that mean for us? Under the ADA, and 504, so now schools, we know they don't want to pay money, but now they're financially on the hook, so that can be a warning to schools.

 This case has got a lot of attention. Really, it's just horrific, the educational situation Miguel had. At the same time, it's extreme but probably not that uncommon when we are thinking about kids, deaf and hard of hearing kids who are really disserved in terms interpreter quality, in terms of parents getting information, his case is extreme, we see issues with deaf and hard of hearing kids sitting in classrooms, the interpreter didn't show up, they're not qualified, extended absence, they're not getting it. I think this is a warning shot that schools need to shape up, because they can be fiscally responsible for that. I don't know, Tawny, if you want comments to add on any of those?

» Please just making sure that we understand that with FAPE, we need to understand that the school district definitely is keeping that child in their school district. They're not providing anything, they don't have staff, proper qualifications and they don't have the skills. So it's not just hurting the students themselves, but it's hurting the school as well. Because if we're talking about a school that has resources, and partnering with the school for the deaf and other districts, and pulling resources and working together, they should have enough education for the interpreters and for the deaf individuals but the schools that don't have them around providing them. We do not have enough teachers. Also, it's reminding families to be assertive and to advocate for yourself, talk with your district but also partner with the different organizations that can help.

 And you need to ask for help, because many times it's not clear about what they should be providing or not.

 For rich—language environment, the parents need to know how that is provided and what they're doing. And the educational system needs to partner together, again, to work together, to make sure that the child is benefiting from all of the services they can provide. And we're talking about that with all of our families.

 »  So with our time left, I just want to mention a couple more things. The Perez case and the other ones, Riley which was a while ago but still relevant, we can see there's issues with the i—d—e—a law, it's not perfect, it has flaws at the same time it does require reauthorization every ten years and last reauthorized in 2004. So that was over twenty years ago, so we're trying to figure out where things stand. Attention has been brought to bills and that seems to be on hold, everybody's in a waiting pattern but in the meantime, we can talk with other organizations, blind Os and that leads me to this bill, the Cogswell and Macy act. The goal was to improve services, amendments to the i—d—e—a. And I don't think it's going to pass this year but it is up for discussion. We're making amendments, pulling together ideas, hopefully this will lead to a policy change.

 We had a great educational advocacy summit a couple weeks ago. A bunch of schools were there. There were over 60 high schools from all different states, so they were able to meet the legislatures so it was a great experience and they all seemed supportive of the legislation and the bill, so if you were interesting interested, you can ——

» I think we have two minutes, perfect. We'll leave you with additional resources for additional questions purchase so rights law.com. I have to warn you, it is kind of a, it's not the most beautiful, visually friendly website, it's a lot of red on white but it a treasure of information related to special ed, you have to dig to find it deaf—specific but a lot of great information there. National association of the deaf, advocacy launched by Tawny Holmes Hlibok in 2012, and contacts for the NAD which will come to me, and each state as a training center, you can just Google your state, and a wealth of resources, in addition to the federal laws, there's a state overlay, and we have 50 states plus the district of Columbia and territories, so each one has its own overlay, so that's another helpful, helpful resource.

 »  And thank you, thank you, thank you. Fielding any questions? Any questions? Anyone want to go back to the chart?

[No responses].

 »  Thank you for your presentation. I had a question. About the difference between... The... If you were to get an IEP versus a 504. I understand that the 504 is not a legal document? That a parent could use in Court if the schools did not follow it, where the IEP is; could you clarify?

 »  Thank you. That's a good question. So the reason for that is because, an IEP is basically a contract, right? It's got signatures on it, it's a contract from the family.  504 plan, there's not contract it's just a list of services that the school will provide but there's no signatures, the family doesn't sign off on it. So there's no contract, that's of difference for the delineation, so the IEP is the special education approach so maybe additional tutoring time, a teacher of the deaf is going to come in. With the 504, it only focused on accommodations, that's it. No special education, so it might be FM transmitter, captioner, interpreter, that kind of anything. Yup. Okay. Any other questions? One more? Going once? Going twice. Okay. All right then, thank you, thank you.

[Applause].

[Applause].

[Applause].

[Captioning concluding, have a good day].