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# Grand Rounds: A Series of Unfortunate Events, presented in partnership with the University of South Dakota

Presenter: Jessica J. Messersmith, PhD; Lindsey E. Jorgensen, AuD, PhD; Jennifer Phelan, AuD; Rachel Barrett, AuD; Jacynda Gellhaus, MS; Gabriella Emme, BA

- [Host] It's my pleasure to welcome back a wonderful group of clinicians and students from the University of South Dakota. This is the first of our annual grand round series, and I'll hand it over to Dr. Jorgenson to invite on the rest of the group. Over to you.

- Thank you so much for having us. My name is Lindsey Jorgenson and I'd like to introduce the group of us that are here today from the University of South Dakota. We are from the Department of Communication Sciences and Disorders, and all of us here are audiologists or audiology students. And so I will get forward, go forward with this. And so the presenters today, or myself, I am the chair of the department and the clinic director of our USD speech language and hearing clinics. I have Dr. Jessica Messersmith and she is also an audiologist. She's the associate dean for the College of Arts and Sciences, as well as a practicing audiologist and one of our professors here in the department as well.

Dr. Jennifer Phelan is here as well. And she is an audiologist and our clinic coordinator for audiology. She as well sees patients here and teaches within our clinic. Dr. Rachel Barrett graduated in May from our AUD program and is currently working at a private practice in Wisconsin and we're excited to have her back. It's always nice to have our recently graduated students with us. Gabriella Emme is a third year a AUD student and she has a quite a background in music and so I'm really excited that she wanted to be part of this as well. So she will be an audiologist.

And then Jacynda Gellhaus is here as well. And she actually has a master's degree from University of Arizona, Arizona State, I could never remember, sorry. Arizona State within the interaction of neurology and cochlear implants. This is our team. We're really excited to be here with you today. So our disclosures are listed here and we have a variety of things with AAA and different, obviously our employments with either the University of South Dakota or the private practices.

We have no real relevant financial or non-financial disclosures. The AudiologyOnline is going to make a donation to our audiology program for giving this presentation, and it does not focus specifically on any specific service that that are provided. The views expressed here are that of the authors and not the state of South Dakota, the South Dakota Board of Regents, the US government or the Department of Veterans Affairs.

All right, here are the learning outcomes that you should get from doing the, from participating in this presentation, we're gonna talk about some best practices with hearing aids and cochlear implants, as well as describe how to interact with the device manufacturers and educational within the penal system. And then how to implement methods for providing care in the series of unfortunate events. So that's what we mean by the series of unfortunate events. Some of these events are things that happened within our clinic. Some of the things are things that we picked up once the people came into our clinic, and some of them just kind of happened alongside our clinic. So we're not perfect and neither are the patients that we see.

And so we wanted to describe some ways where we have run into some hiccups and what we could do about it. And so we're really excited for you guys to be here with us today. So the rest of us are gonna go off on video, and I'm going to be introducing Dr. Jessica Messersmith as our first presenter. She will be presenting about Tigger.

- Thank you Dr. Jorgensen. I am so happy to be here with you all today. As Dr. Jorgensen said, I hope that you really gain a lot out of these cases. We have quite a few cases that we're gonna go through today. So we'll each be going fairly quickly through them. Really just trying to hit some specific takeaways as we consider that those unfortunate events, those situations that maybe led to a circumstance that we wish wouldn't have occurred, or a circumstance that maybe negatively impacted this individual's outcome. So as Dr. Jergensen said, I'm starting out with Tigger. So Tigger when they came to our clinic was fairly young and they were diagnosed with a bilateral,

or excuse me, yes, a bilateral sensory neur hearing loss in the profound range when they were three months of age, at which time they were fit with bilateral amplification and proceeded down the road towards a cochlear implant evaluation, eventually receiving a cochlear implant bilaterally when they were 13 months of age.

This person received this internal, or excuse me, received their cochlear implant several years ago. So at the time, their internal was a CI 512. At the time that they received their cochlear implants, they were using a different processor than what they're using today. At this point in time, they have been upgraded and are utilizing an N8 sound processor. So when we consider this person, this child, in the younger years of their life, their family situation, though stable in parenting, the location in which they lived was very transient. They bounced around from several different locations, which really created a situation where we had to, as a clinic, be very on top of and intentional in maintaining our contact and communication with them to ensure that we were seeing them back for routine follow-up appointments, both when they had their hearing aids as well as when we transitioned to the cochlear implant.

And that the transient of, the transiency, excuse me, of their living situation really probably hit a peak in that first year after receiving their cochlear implants. And when working with them, that led to a lot of creative approaches to how to keep devices working, how to keep batteries charged, how to keep this equipment in really high functioning levels so that this child could be recognizing the progress that they really ideally should be receiving. Now, with all of that, it was also of equal importance that we continue to provide this individual really high quality care and high quality programming. So when fitting cochlear implant users in our clinic, we utilize a combination of what we term objective measures as well as behavioral measures to be able to determine what that electrical dynamic range should be.

For a point of reference, recognizing that not all of you on this session today are users of, are familiar with cochlear implant programming software. So what we're looking at here is a screenshot of what you would see in that programming software for a cochlear implant. And when you look at this, you see those lower green bars and then you see those red bars that are higher up on the screen. The green bars towards the bottom, those are what we term the lower stimulation units. You may hear those referred to as T levels as well. The red bars up at the top, those are upper stimulation levels. That if you want to consider is that's the upper level of the dynamic range when we measure it through electrical stimulation.

Through cochlear implant programming, our primary goal is to set those T's and upper stimulation levels at levels that create an electrical dynamic range that gives that user good access to sound around them, while also providing them appropriate loudness growth from soft to loud. That goal of fitting that electrical dynamic range, that's where those objective measures and behavioral measures come into play. Behaviorally, when we measure lower stimulation levels and upper stimulation levels, it looks a lot like other aspects of audiologic clinical practice. So when setting lower stimulation levels, those Ts, we measure those really similar to how you would measure thresholds in a sound booth, go ascending and descending in that presentation level until we find a point at which they're responding to it just over 50% of the time.

And this is for a cochlear device, so it's that just audible position. For our upper stimulation levels, we do a loudness growth function and we adjust the level of that electrical presentation, that electrical stimulus, define the level at which the person judges it to be loud but comfortable. So when programming this child using behavioral measures of loudness, these were the respective levels for those Ts and Cs for the left and right ear respectively. Now, as I said in our clinic, we compliment that we really rely on objective measures as well. And the primary objective measure that we utilize in our clinic for setting the electrical dynamic range is the ESRT. The electrically evokes to

PDL reflex threshold and that ESRT has been shown repeatedly to correlate very strongly with those upper stimulation levels, those C or M levels.

And we find when looking across public data as well as within our own clinic population, that those ESRT levels usually fall within six to 20 clinical units of the upper stimulation levels measured behaviorally. Performance wise, ESRT programming has also been shown to provide really good outcomes with patients. We see comparable speech perception results, and we even see that listeners prefer an ESRT based map as opposed to a behaviorally based map. And this evidence that we collectively see regarding ESRT, as well as our clinical practice with, or excuse me, our observations and our clinical of our patients have really led to our clinical protocol of utilizing ESRT on every individual who has a measurable ESRT. And that approach is now supported in the various CI practice guidelines that exist.

So your ACIA guidelines, your AAA CI guidelines, both recommend utilizing ESRT as a component and really supporting that belief that ESRT should be completed on every cochlear implant user who has a measurable ESRT. So just a quick showing of what that looks like. I always like to show this because oftentimes when people hear of ESRT, they think, "Ooh, I don't know how to do this, so I'm not going to do it." And I really stress that ESRT, if you've done acoustic reflex threshold testing diagnostically with someone using acoustic hearing, you can do ESRT. It's the same thing except for rather than stimulating that contraction through acoustic stimulation, you're stimulating that contraction through electrical stimulation. And when you do so, you see this lovely deflection, that contraction of the stapedius muscle just as you would for an acoustic reflex.

And that's what you're looking at on the slide here. Just like with acoustic reflex threshold testing, when measuring ESRT, we like to see that growth of response. So we increase that stimulation level through the cochlear implant to make sure that that

deflection grows in size. And for this particular child, when we measured ESRT, we found a much wider electrical dynamic range than what they were programmed behaviorally, which actually we commonly see, particularly in kids. Children who don't have prior experience with listening really struggle with making loudness judgments and providing behavioral indications of when that sound is at that appropriate upper STIM levels. And so ESRT is a really great tool to be able to utilize to give you confidence in setting that electrical dynamic range for our pediatric populations.

Now I wanna jump to where we are now with this child. So if you recall, one of our unfortunate events was when they were first received their cochlear implant in that first year of life, when we were really dealing with a transient living situation and needing to support them where they were. Here in teenage years, we have really, as a clinic, I feel been supporting this child even more so. So this child, when we saw them approximately a year ago for their annual evaluation, was transitioning a name as well as their outward expression of gender. And so we found out after that appointment that we were one of the first spaces where this individual felt comfortable expressing their true self.

And I feel that was a really positive indicator for our clinic and this stability and security that we provide to our patients so that they, when they enter our space, recognize us as a safe environment for them to present who they are and to present a person that we really can help them to be able to live their life and not have that hearing be an obstacle that's placed in their path. And we see with this child, they're doing amazingly well with their cochlear implants. We're seeing really high scores in our AZ bios, we're seeing really great aided thresholds with those cochlear implants in that ideal range between 10 and 30 db where we wanna see them. And when we consider that, we really then have to stop to think about with this child what potentially comes next for them.

We want to continue to be able to support them in whatever stage of life they are, continue to provide that safe and secure environment where they can be open and honest with us, as well as being able to support them in where they choose to go next with their life, what their living situation may look like in the future as they transition into high school and adult years, as well as supporting them and identifying if they continue with our clinic when they become an adult and maybe relocate elsewhere, as well as identifying what comes next in terms of college or higher education and career. So working with this child has been one of the highlights of my career. And that is largely because we've faced so many quote unquote unfortunate events where we've really had to think creatively on how to support them and serve them to the best of our ability.

- Thank you so much, Dr. Messersmith. You know, it really seems that in a situation of unstable situations, you were really the stability that this child needed and that's really evident by the fact that they were willing to share their true self with you. Boy, I have a whole bunch more questions, but I'll save those for the end. So next up I'm really excited to introduce Dr. Rachel Barrett. So Rachel had a really interesting experience during her fourth year that she completed in London. And so I think that the case that she's gonna present today is actually someone from that fourth year externship experience. So welcome Dr. Barrett.

- All right, thank you Dr. Jorgensen. So yes, today I am going to be talking about my patient named Ted. This patient, like Dr. Jorgensen said, is one that I saw during my externship experience at a private practice in London, England. And now I recognize that the healthcare systems between the US and the UK are very different. However, I feel that this particular patient interaction might resonate with many. So that being said, Ted is a 76 year old male and during the initial consultation at our office, he described himself as being very active and social with hosting dinner parties, with going to theaters often and socializing with friends. So he's incredibly active. And when he

arrived for our appointment, he was wearing receiver in the canal hearing aids with open domes.

So the serial numbers on the devices show that they were fairly new, about one year old or so. And so he had gone on to describe to us that he got his hearing aids through the National Health Service or the NHS. So the NHS is the country's free national healthcare. So the devices and all of its services are completely free to the UK residents. So he wanted to schedule a follow-up appointment with the NHS provider that he had gotten the devices from, and he was told that it would be a three month long wait. So that is ultimately what brought him into our office. So he had seen this NHS provider one month prior to our appointment where he had initially received the hearing aids and then before that he was on the wait list just to get the hearing aids for about two years to get them through the NHS.

So lots of wait time. So during the consultation, once again, he reiterated how long the wait has been to be seen again by that NHS provider just for a simple follow-up. And so he was understandably very frustrated with the devices and he didn't really feel like he was getting a ton of good benefit from them, especially given, you know, his busy and very active lifestyle. He was having conversations in the presence of a lot of background noise. And so that was definitely an area that he wanted to see improvement in with the devices. And then another concern that Ted had coming to a private practice as opposed to going through the NHS was cost. So with the NHS, once again, he was able to get the devices for free and he wasn't terribly keen on having to pay for the appointment at our office that day.

So after, you know, discussing his concerns and his medical history, I went on to explain what the appointment would consist of, you know, the tests that we would be doing, what they looked at, why they're important, and most importantly, I also kind of touched on the costs associated with it since that was such a big concern for him. And

so he was given, you know, the standard cost for the comprehensive hearing evaluation. And then he was also quoted another amount for performing the ear measurements and verification. So for testing, a standard audiologic test battery was completed with air, bone, and speech. Results revealed a moderate sloping to severe sensory neural hearing loss bilaterally. Aided speech and noise testing was completed with the devices before the changes were made.

So just simply when he came in with the devices and how they were set that day. And this test revealed a 10 db SNR loss. Ted was counseled and educated on the results of the hearing test aided and the aided testing, excuse me, I did go on to explain the benefits of performing real-ear measurements and once again reiterated the cost that would be associated with performing those tests. And then he did end up giving his approval to perform the measures. So the dome was changed to a closed dome and then feedback manager was run in the software. Real-ear measurements were run, including RECD, unaided gain, occluded gain, and the aided response testing. And then fine tuning adjustments were made in the software in order to match targets for the aided response testing.

And I would also like to take a moment to acknowledge that it may not always be possible to make adjustments within the software of devices purchased from outside centers. However, in this case, the devices were not locked. And so I was able to do so at that appointment in our office. So following the adjustments, Ted reported a noticeably more clear sound. We put him back in the booth to do another aided speech and noise testing and this time using the newly programmed devices. So results this time around showed a six db SNR loss. So a little bit of an improvement. And when he came out of the booth, he actually even made a comment about how he noticed that the test was easier this time around than when he first did it, before the devices were changed.

So we went through, you know, the use of the program buttons, volume changing, and then the care and maintenance of the devices just to give him a little bit of a refresher. And so with outcomes, this was a huge successful one. And this was as I was first starting out as a clinician. And so Ted was so confident and an excited, you could really see a noticeable shift in behavior for him. There was noticeable improvement in sound almost immediately. And this was also seen in the aided testing as well. And then also two weeks later, I actually called Ted just to check in and see how he was doing. So not only was he doing better with the devices, but he was also able to confidently converse with his friends at a dinner party that he had recently attended.

So he was really appreciative of all the work that we had done, and I think that it was a successful cost benefit analysis in his eyes. And so he was also very appreciative of us just calling to check in on him and see how he was doing, really kind of continuing that follow-up care. There we go. So a couple of takeaways from this patient experience. I think the most important one that I kind of found, once again, this is as I was first starting out at my placement, it's so important to meet the patient where they are in their journey. This requires a lot of active listening on our parts, but also, you know, offering solutions that would best serve the patient and kind of what their primary goals are, where they wanna see improvement, where we can best help them.

Another takeaway that I had was explaining the value of your knowledge and expertise as an audiologist, as well as the purpose of the tests that you're completing. You know, also, especially in this case with Ted, he was so focused on the cost of all the things that we were doing and so explaining, you know, why each test is so important and that's to justify the cost, especially since, you know, you've built up your value as the audiologist with the knowledge and expertise and experience and so on. And the final takeaway point that I had really was looking at the importance of follow-up care by making it not only accessible for the patients to be able to come in and see you, to get those regular and just sometimes even quick adjustments made, but then also

following up with them to show that you care and want to help in any way that you can while the patient is on their journey. So that is all I have, but thank you so much for listening.

- Thank you so much, Rachel. Such an interesting case, and I do think that that this really, you know, set you up for obviously your future success, but really makes us realize that even when things are not necessarily, you know, what you expect coming in the door, you can definitely make improvements. So I have more questions about this one too, so, I'm excited to, to ask you those at the end. So next up, I'm really excited to introduce Gabriella Emme. She'll be talking about a case that I think just kind of tugs at all of our heartstrings on things you know of an unfortunate events that kind of happened in this child life, that child's life that definitely impacted the care that he receives. So take it away.

- Thank you so much Dr. Jorgensen for that introduction. So I will be presenting on a patient that I have named John. So John is a 17 year old cochlear implant patient. Some important and impactful parts of his case history is that his hearing loss was late identified. In addition to this, when he was identified, previous professionals did not believe the patient had as severe of a hearing loss that the testing had revealed at that time. This meant that the impact of his hearing loss on daily function and overall wellbeing was minimized by some professionals and clinicians. Another important part of his story is that he was labeled a behavioral disorder student. And due to this, he spent significant time in special education classrooms and within these classrooms he was sometimes even completely isolated from other professionals and peers.

The reports from previous clinicians that were gathered from his parents state that when he was isolated, he did not have much access to speech and language. So now that we know his previous case history, I'm going to now fast forward to when his case history from our clinic began. So at this, when he com came to USD, he was first seen

here for a cochlear implant evaluation, where it was still reported that the patient experienced those extreme behaviors that were noted in previous reports. Through multiple different appointments were both behavioral testing and ABRs were completed, it was found that the patient did have a significant hearing loss and qualified for a cochlear implant, and was subsequently implanted.

Post implantation, the behaviors decreased for a period of time and the patient showed benefit from this device. But those behaviors and those reports of those behaviors did subsequently increase up until about 2019. So during the appointments during 2019, it was revealed that the patient was hospitalized for depression and anxiety and having those difficulties and different behavioral disorders as well. It should be noted that during most of the previous appointments, the patient did not engage with clinicians. When he did engage, he really only provided short succinct answers to the questions only really when prompted. Then the patient really wasn't seen between the years of 2019 and 2021. So in the next slide, I'm going to fast forward to that 2021 time. Before I do that, I would like to mention that when we are seeing pediatric patients, we should always be sure that when a parent has concern, which John's family did have, we should look for the following, the root of their concern and do a hearing screening and gain those audiologic results.

We should look at previous hearing screenings and results when available, and also look at those academic and behavioral reports to see what information they are able to provide us. On this next slide, as I mentioned, we're gonna fast forward a little bit. So in 2021, at this time, USD was notified by the family that the patient was now in a local juvenile detention center. And in this phone call, the family wanted to know if the device could be upgraded and if the upgraded device was able to be received, if it could be programmed at the facility prior to the patient turning 18. So we were able to receive that upgrade and once that upgrade was received at our clinic, a CI audiologist and graduate clinician saw the patient at that juvenile detention center.



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So now that I've provided some background information on the patient and his history, I'd like to focus on where these series of unfortunate events occurred for this patient. So within the literature, there is a term that is known as the school to prison pipeline. The image you see on the screen is from the book, "Deaf People in the Criminal Justice System." Selected topics on advocacy, incarceration and social justice. The school to prison pipeline is defined as the failures of the school system to support and educate children with challenging behaviors, which pushes them into the juvenile and adult prison population. Another important term that is used within the literature is known as the school to prison nexus.

This refers to the combination of multiple systems that push deaf youth towards a negative outcome and away from positive rehabilitative resources. We can see on the screen that there are many different systems, also known as Nexus points that can impact youth. For our patient, we can see that potentially language and learning challenges, school and education, literacy levels and treatment options were just some systems that potentially pushed this student towards juvenile incarceration through this school to prison pipeline. On my next slide, I have a few key statistics that are gonna demonstrate the impact of hearing loss and juvenile incarceration. So on the screen here, I have looked at a couple of different data points that I have gathered.

So through data from the Youth and Juvenile Justice System report and the Office of Juvenile Justice and Delinquency Prevention statistics, we can estimate that in 2022, approximately 1% of children in the US between 10 and 17 are served in correctional facilities. When we compare this data from the National Institute on Deafness and other communication disorders, we see that in 2016, about 8% of youth 10 years and above who are deaf and hard of hearing are served in correctional facilities. It should be noted that this data is older though since there's not a wealth of information or statistics on this topic, it's still an important statistic to consider overall. Then when we look at the

impact on incarceration in youth, we can see that this increases their likelihood of being incarcerated as adults by more than 20% and can significantly reduce their chances of completing high school.

Then I'm gonna draw our attention to this last bullet point. When we look at the median literacy rates of deaf high school graduates, we see that this is around fourth grade. So now that I'm gonna have you think about the patient that I introduced to you at the beginning of my slides with the information and statistics that I mentioned throughout this presentation. And when thinking about all of these statistics, this patient, I've kind of gathered a few key takeaways. The first one being that we, that advocating for our patients is really, really important. So advocating for our patients and listening to the reports and questions that the family asks is important. We wanna make sure that we do everything in our power to ensure that they are receiving access to the services they need.

My next takeaway is that early identification and intervention matters. We know that early intervention is critical for auditory and language development, and we can see through data in 2015 when we specifically look at children with hearing aids, those who are fit with hearing aids have better early language achievement than children fit later. And lastly, we should consider how different systems can impact our patients, whether they are language and learning challenges, school and education, treatment options, or other system and nexus points. We should know that these could potentially impact our patient's trajectory. We want to ensure that we move students who are at risk of incarceration off of this school to prison pipeline. And with that, I would like to thank you for listening to my part of this presentation.

- Thank you so much, Gabby. You know, this was one of those situations where I guess we just didn't really expect to see him in prison, but you know, we all wish that we could have done more, but we definitely made his his life better and hopefully can help

turn some of that around. So thank you so much. I have more questions about that too, so thank you. All right, so up next I'm excited to introduce Dr. Jennifer Phelan. So I am gonna put a caveat on this one and say, Jen is actually going to show pictures of this actual patient. So yes, we know we do have signed releases, everything like that, so I just wanted to put that out there that we definitely have those signed releases. So thank you so much, Jen. I'm really excited to hear about the little girl that you saw in Guatemala.

- Yeah, so, you know, I love that when all of this went out and Lindsey said to us, "Okay, let's pull cases together." And for Rachel to have presented on a case for when she was in Great Britain and for Gabby to talk about how important early intervention is, because I'm gonna bring up and bring both of those back, because we're gonna go international again, we're gonna go, this time we're gonna go to Guatemala and we're gonna talk about the early intervention in terms of universal newborn hearing screenings. So this is not the case I intended to present on, and all I can say is going on a service trip is something I've wanted to do. I've been an audiologist for just over a decade, and I remember attending presentations about humanitarian trips even when I was in graduate school.

And I just had my first opportunity to go this year. And it changed the way that I see audiology, the way in some, the ways I practice audiology. And so my first plug is going to be, if you've ever wanted to go on a trip, do it because it is amazing. And being a decade in it really kind of reinvigorates things. And so I loved it. And so I came back and said, "Okay, I'm gonna talk about this case instead." So went on a trip to Guatemala. And so to get to Guatemala, it's a trip into Guatemala City. And then I'll show you on a map where we actually were. So we took a six hour bus ride from Guatemala City.

So we were in very rural part of the country. Alejandra, which is not her real name, the pictures are her, but that's not her real name, is was a three-year-old girl. At one year of age her family reported she had a pretty severe head injury, mainly on the left side of her head. So this was two years post that accident. The report was after this accident happened, she did go to the doctor and asking whether there are any tests run CTs or x-rays. The family reported, they didn't recall any, that none of those were done, that doctors didn't think that there was a skull fracture and basically just surface injuries, scratches and things like that were cared for at that time.

The family did say that, and we experienced, that she had limited verbal language, so Alejandra was babbling, but really a lot of her communication came through the use of gestures and honestly this independence we saw, so if she wanted something, at one point I was talking to family, so she came and we'll see in the pictures later, she came with grandpa, aunt, mom and younger sibling. And so at one point we were talking and she wanted mom's phone and so she got down, she went into the bag, dug through the bag and got the phone out and handed it to mom. And mom was able to do and find what she was looking for. So, you know, that's how she, that's how she did what she did.

She just moved around her environment very freely to be able to get the things that she wanted and needed. And so in this, so talking about Guatemala and talking about a three-year-old, we think, well, you know, do we know anything else about her hearing? Do we have anything up until then? And so it's important to talk a little bit about Guatemala. As a country, there is no legislation requiring newborn hearing screening. Guatemala, according to the World Health Organization is considered an upper middle income country. Prior to 2018, there was not a universal, there was no universal newborn hearing screening. So there's no legislation, but there was nothing that was done. In 2004, there were efforts to put some high risk programs together and then there were other sites in 2008.

But prior to this 2018, there really wasn't anything really standard. In January of 2018, a pilot program was created by both the Rotary and this other organization to be able to do newborn hearing screenings through OAEs. And they had, I believe it was one ABR unit that they're kind of, that travels. It's important to note. So here's one thing that I think, you think about as a country and then you think about worlds colliding, right? So when we were on this trip, we kept hearing about Patty, the audiologist in the country, Patty, the audiologist in the country. And I went to literature and there isn't a ton of literature, but I went to some of the literature about audiology in Guatemala and in one of the articles it actually mentions the only practicing audiologist in the country is Patty.

So, you know, she really is it and she's in Guatemala City. So if you look at this map, and you can see Guatemala is just south of Mexico. If you look at this as a country, how spread out everything is. And so where the blue stars are, those blueish gray stars, that's where they're doing newborn hearing screenings currently, where the program is set up. And then the red one was from this article, they were pointing out that this is where another one was going to start, that black dot I added, because that's where we were. So that's Nuevo Progresso where we were seeing these families. And so you can see the distance, right? So Alejandra was not born in a place where there was newborn hearing screening and not something she had access to.

So we don't know what her hearing was prior to this accident. We don't know if the accident potentially impacted, but it's just a bit of her history that we want to gather and that we want to know. And asking those questions and having the family be, you know, the the ones to give us as much information as possible. In not having those records, which of course we would've loved to if we could have gotten them. So that's just a little bit about the system in Guatemala. If we take numbers from the US, so we have in this CDC it's estimated three out of every thousand children are born with a hearing loss in the United States.

So if we extrapolate that just a little bit, it's estimated, the numbers I have are from 2017, but it's estimated the total number of births throughout the country of Guatemala is just over a thousand, 1,125 per day, right? So if we do just a little bit of extrapolating, that means that on average there's three to four children born in Guatemala every day that have a hearing loss, right? And they have these five centers and so it's good, I'm glad that they have them, but they're also not all babies are being screened. And so that's why trips like this and service service trips that do go kind of out into these other areas are really important, because we can do some of this work and help to help all of the residents, but specifically make sure that we're looking at the kids in the country.

So for Alejandra in particular, so this is a really interesting setup in that I've never seen a clinic that had all of its patients there at the beginning of the day. We had breakfast at seven o'clock. By the time we finished breakfast, all of the patients were there for the day. Not just the first patients, not just the morning patients. So they showed up, because they were traveling for hours. This family had to walk for several hours before they were able to get to a place where they were able to pick up a bus. And they were nicknamed the chicken buses, because my understanding is that people brought chickens on the buses with them. So they took the chicken bus then to be able to get to the hospital we were at.

And the hospital we were at in Nuevo Progresso was built just for this, the clinic was on the first floor and actually the quarters where we stayed were on the second floor. So it was built to have groups come in. So, you know, this was a whole day process for these families. And so we really tried to get everything we could in the appointments as much as possible. This group is going back, so they're gonna be going back again in October and then I believe in May of next year. And that's one of the reasons it was, I wanted to, yes, go on a trip, but also a trip like this, because of that continuity of care.



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It wasn't just drop in and we did this and then we never went back. So, you know, it was fabulous to be able to talk with patients about how okay and schedule for your October appointment just like we do here in the States. So for Alejandra, when we were doing her testing, she did, we did do behavioral testing and it was done with fair reliability. I am gonna give a shout out to Dr. Jorgensen, 'cause she is the one who did it. She will tell you time and time again, like she rarely works with kids. It's not necessarily her wheelhouse or where she's most comfortable, but she was able to get great results. She got this nice eye shift.

So, you know, she reported every time she played this pulse tone, Alejandra would like look to that side and look to that side like what the, what's going on, what's over there? And so she was able to get fair reliability and which is great and in, you know, honestly in the States and when you have a timeframe where you have your appointment and your appointment is however long, 45 minutes that might be like, okay great, we have a great starting point and let's go ahead and reschedule and bring them back. Well we're not gonna, we weren't gonna do that in this situation because the family had traveled for many, many hours to come and see us. So to be able to support the behavioral testing we got, it was recommended that we do an ABR.

And so we were able to bring some ABR equipment down with us and we wanted to be sure that we were making the most appropriate recommendations and that we were for sure that our results were what they were. And so then I was able to complete the ABR same day. And so we brought the Viva Sonic unit with us and so she was seen earlier in the day and then waited, family waited in the courtyard. And so as I was doing the things I was doing, we added her to my list for the day and I said to the family, "Okay, let's see her after lunch." And so the plan was that they were going to relax a bit, they were gonna get some lunch and then I was gonna see her afterwards and it actually ended up working beautifully, because she had traveled so long and she had been up for so long and after she ate lunch, she was toast, she was done.



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She took a fabulous afternoon nap and such a great nap that we actually were able to take her from clinic across the street, 'cause they do have an OR there and there was a room right off the OR that was nice and quiet that we were using for the unsedated ABRs and she slept. We had our afternoon rainstorm that came through and everything, and she was just a champion sleeper. And so it was one of those things where we couldn't have planned it better, right? We do those things in the States and we call families and say make sure they're hungry, make sure they're tired. So we bring them in and they're gonna sleep for us and we cross our fingers and this was the case where we weren't going to be able to get her on to our sedation list for the day, right?

The OR already had their plan. And again, we didn't want to have to push it to the next day, 'cause the family wouldn't have had a place to stay. So doing this unsedated ABR was the only way we were gonna be able to get it and she was quiet and with the viva sonic. So even if she was awake we probably wouldn't have been able to get information. But it went so much faster and so much easier, because she took a fabulous nap. The findings from the ABR supported the be behavioral findings, which was that we got a flat moderate sensory neural hearing loss on the right and we did get a, we got some responses in the left ear and then we went down to no responses.

So moderately severe to profound in that left ear. And so we were able to get all of this information for her so that we could make our recommendations and sort of what to do next, which, what to do next was a hearing aid on that day. So she woke up from her nap, we talked to family and we did all of this on the same day. A right hearing aid for this visit, continue to monitor with behavioral testing. So again, that group is going back in October and so I have her on their list to be seen in October. They already have their appointments scheduled and at that point determine if a left hearing's appropriate, what else potentially the family would want to do and just see how she's progressing and how the family feels like she's doing.



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So on your screen we do have two pictures here. And so the one picture is us in the main, I don't know, it was kind of like a catchall room. It was like really the main testing room. And so there was testing done in the back three stations with the Kudu Wave we used. And then we actually had three fitting stations as well. And so she's three and she's sitting for us. We had a table, we had to move. We brought a, we had an audio scan, we had to bring the audio scan down. So for her, because she was just so little that our table, it was the speaker would've been too high, but she was able to sit, we were able to set up and get everything, get everything going to where we were able to verify that hearing aid for her.

The other picture is myself with the family as well as a graduate clinician from another university that was able to come on the trip. And I will just say that everyone and this family was no different, just incredibly thankful for us being able to do all the things we were able to do and within that one visit, within that one, within that one time. And so it was really great to go really from start all the way through to getting her that hearing aid fit in that one visit and in that one day so that it wasn't just, we kept having to plot along. You know, lost to follow-up is huge. Lost to follow-up is something that we all worry about, right?

Whether you're working with kids and you're talking about universal newborn hearing screenings, lost to follow up on babies who don't pass, all the way to working with adults. We just call it something different, right? We call it tested, not sold. If we're, you know, if we're talking about maybe a more private practice setting, right? Individuals who we know who we would be able to give services to that are not coming back. For whatever reason, they're not coming back. And so it's important for us to be able to really have this go in the same day so that we know that we're being able to provide these services and get them on the schedule. 'Cause we know if they walk out with an appointment, it's a lot more likely that they're, that they're gonna come back.

And so we already have that plan. We already, the family already knows what the plan is to be able to move forward and know what's gonna happen in October and why they need to come back in October, because we want to keep monitoring and see is there anything else we can do? What else, what else needs to happen? And so it was really great to be able to do everything in one day in really one space, in one in one room, like you can see in the picture. And so my takeaways are that we all know newborn hearing screenings are important, but we also recognize they pose challenges to countries without the infrastructure for follow-up care.

And I honestly, I don't even think it's, I think follow-up care, the infrastructure for follow-up care is where all of us, where everybody, there's a hiccup, right? We need to be sure we have good communication, we have to be sure that families understand why it's important to follow up. And so I love seeing that other countries are recognizing the importance and looking at early intervention and doing the best they can with what they have. I think it's amazing that a country that has one audiologists has five sites, right? And it's techs that they train and all of this, but she's also one audiologist in Guatemala City. So again, some of those things that we need to think about, but that infrastructure is incredibly, incredibly important.

We need to recognize there's a lot we can do even if we're less than optimal testing environments. And I think that's really important. You saw that one big room. And so we can really do a lot. I work with, I work with Lindsey Jorgenson, so I ha takeaway is real-ear measures, right? If we can do real-ear measures on a three-year-old in a pop-up clinic in Guatemala, we can do them in our clinics in the States. You know, I can't speak to the time. These individuals were there, we were gonna take the time. That's just the nature of this trip. But the reality is some of the things that we, you know, that we might tell ourselves or the questions we might wonder, you know, can we do real-ear? Yes, yes we can, we can do real-ear. It doesn't take that much time.

And if, again, if we can do it in what I call the popup clinic in Guatemala, we can do them on really all of our patients in the US. And then it's important to recognize that obtaining information from the families, from peer reviewed research and getting medical records if they're available, is really key if there's something that you haven't seen before. Now again, we didn't know these families made appointments, but we didn't know why, we didn't know what all of this was. And so, we didn't know that she had had a head injury. So when we kind of go into this unknown, we needed to interview the family, we needed to go ahead and look at some of the research that was out there that just taking out phones and looking up some things real quick. And in this case medical records weren't available, but I would've loved to have seen some of those records if I did have them at my disposal. So that is my case with Alejandra and impactful and I'm excited to get to go back at some point.

- Thank you so much Jen. You know, really what a great experience and what an amazing family. You can see in that mom's eyes she was exhausted, because man, she, you know, walking three hours with two kids and being there all day. But, you know, really the care that we were able to provide, I obviously have some more questions, not as much seeing as many pediatric patients except for, apparently I'll see pediatric patients in Guatemala. Here obviously there are people that are, that are more versed in that. So next I would like to introduce Jacynda. Jacynda is gonna talk to us a little bit about Harry. Harry, I'm super excited to hear about, 'cause he is part of our biannual Rapid City trip where we go out and see some of those kids that we've been seeing for a long time with cochlear implants.

- All right, thank you Dr. Jorgenson. So meet Harry. Harry is a vibrant nine-year-old boy. He loves music and making others smile. And as Dr. Jorgenson said, we see he on our biannual outreach trip, which is located in South Dakota, Rapid City, South Dakota, which is about six hours away from where we currently are on our side of the state.

And the University of South Dakota provides services to this location where we reach out to families in the tribal, ranch and rural communities. And these unique communities offer, they're different in many different aspects. And so this includes a lower household income and a slower pace of life. That side of our state is also considered our frontier with a population density of less than six people per square mile.

So all these factors contribute to significant cultural differences. And our research efforts extend, or our outreach efforts extend to this region, aiming to address the limited access to pediatric audiology and connection to speech services. So Harry has a bilateral conductive hearing loss and utilizes cochlear's BAHA 6 Max with a soft band. Harry also has a diagnosis of goldenhar syndrome. And Goldenhar syndrome is a congenital condition that impacts the development of one's eyes, ears, and spine. And additionally, one's facial structure and other organs can be impacted by this syndrome. So Harry has some cranial facial anomalies, including cleft lip and palate, and a tracheal stenosis, which he does use a trach and a feeding tube for. So prior to seeing Harry in this past spring, we reached out to his grandmother to help facilitate setting up this appointment.

And his grandmother had reported that Harry recently has gone through a significant amount of trauma in the past eight months and she had just gotten custody of him. So due to family circumstances Harry had not attended school, worn his hearing aids, and was exposed to violence as well as illegal substances in the home. His grandmother did not know the full extent of his experiences, because she did not have contact with him at that time. So children with multiple disabilities experience a range of challenges due to the cumulative effects of trauma and disruption. And these effects have consequences that have, that affect many different parts of their lives. So for trauma, whether it's stemming from abuse, neglect, or other adverse experiences, it can



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significantly impact the overall wellbeing of children with multiple disabilities and often exacerbating their struggles.

So the key, the trauma that they endure can manifest in many different ways, and this can be present as emotional and behavioral difficulties, anxiety and some impaired social interactions. This can also affect their ability to learn and engage effectively in educational settings. So trauma and disruption in the home can harm a child's education and adverse experiences can impact their cognitive and emotional functioning, making it hard to focus, learn, and perform well in school. Unstable home environments can disrupt routines and limit access to educational resources leading to absenteeism and academic struggles. So in Harry's case, he was set back by not having the opportunity to go to school for those eight months. The home environment does play a crucial role in the development and wellbeing of children with multiple disabilities and in children with hearing loss.

And however, the impact of trauma and disruption within the home can disrupt the stability and the nurturing atmosphere that these children often require, a chaotic or abusive environment as well as an environment that might have some financial struggles, can hinder their growth and their overall wellbeing. So these lack of resources may limit opportunities for those early interventions, which is crucial for those outcomes and those long-term effects. Another aspect that families often face is navigating the complexities of the medical system. And as we know living in the United States, this can be overwhelming for families with children who have multiple disabilities. Appointments with various specialists and the need for assistive devices as well as obtaining an insurance coverage can be really stressful.

We often have a web of providers that offer supports and it's really challenging to navigate and often leads in delays to having necessary treatments and interventions. So addressing the effects of trauma and disruption often requires a multidisciplinary

approach and accessible mental health services, trauma-informed care and interventions that address the specific needs of children with multiple disabilities and hearing loss are crucial. By recognizing and addressing the multifaceted challenges that these children encounter, we can strive to create a more inclusive and supportive environment that promotes their overall wellbeing, development, and resilience for the child. So as we just kind of went over, trauma and disruption can have a huge impact on the child's outcome and there's often no direct roadmap for success.

And so for a child who has experienced trauma and disruption, there is a lot of essential components that might need to be added. The first being sensitive communication. Effective communication is crucial when working with children who have experienced trauma. And this might include in having non-threatening approaches using AAC devices when necessary, and then respecting boundaries and creating that safe environment that we had talked about earlier. We wanna make sure that the child feels comfortable expressing themselves, and it's crucial for building that trust and promoting healing within the child. Audiologically this can also mean providing more narration and a more in-depth explanation of what the child and the family will experiencing before the appointment and during the appointment.

So as part of our roadmap, an interdisciplinary approach is also key for working with children who have multiple disabilities, but it's also key to addressing the complex needs of a child who has experienced trauma. So this comprehensive approach can ensure that all of the aspects of the child's development and wellbeing are being considered and supported. Trauma-informed care. So implementing trauma-informed care practices is essential for providing appropriate support for our patients. And this approach recognizes the impact of trauma and emphasizes creating a safe and empowering environment. It involves training professionals and emerging professionals to understand the effects of trauma and implementing those sensitive policies as well as using evidence-based interventions that promote healing and resilience.

So as we are talking about trauma, intergenerational trauma is also important to recognize. And this is especially important when working with children who have experienced disruption and trauma in their homes. Incorporating sensory regulation techniques and integrating behavioral supports can help address those emotional and behavioral challenges that may arise as a result of trauma. So providing a supportive and nurturing environment that promotes that emotional regulation can aid in the healing and breaking of that cycle of intergenerational trauma. And lastly, supporting resilience and hearing. So fostering that trust between caregivers and service providers is crucial for supporting those families through the healing process. We have to adopt a non-judgmental approach that respects the family's cultural background, values and their experiences that they have had.

Emphasizing a family-centered approach is really key for a lot of these children, and it ensures that the caregivers are actively involved in the childs care and promoting that sense of empowerment as well as building a strong support network within the family. So what did this look like for our patient? Our plan for Harry, first and foremost, was to implement trauma informed care at this appointment. We had a little bit of information going into it to kind of prepare ourselves for what we are going to be experiencing. And as we were seeing our patient on outreach, as Dr. Phelan was saying, we do take the time to make sure that we are getting all of the things done that we need to in that appointment.

And this involves many different components that are aimed at providing holistic support as well as addressing his specific needs. So our plan included family support and engagement. And we did this by recognizing the importance of involving Harry's family and prioritizing providing them with support as well as engaging them in the care process. This looked like open communication between the two, really hearing out what the grandmother and mother who attended the appointment were saying about

their experiences and the struggles that they were facing. We used active listening strategies and we offered resources to assist them in navigating on their journey. We also employed a multidisciplinary approach, and by doing this, we used, we had professionals in a lot of different disciplines such as medical, educational and mental health fields.

It's important to note that on our outreach trip we have speech services as well as South Dakota Services for the Deaf consultants are there. And we wanted to ensure that Harry was being looked at as the whole person. This included connecting him with a cranial facial team. And this was really important, because when he was younger, it was recommended that he had been seen by a cranial team to address a much needed surgery that was recommended to him. And at that time, money and time were factors. That did impede his care. So we were able to call and get him reconnected to a surgical team. And just recently, we were happy to receive an update that he has been scheduled for surgery.

So they were able to make it to that appointment. And that included getting connection to other services. So we were facilitating his access to services such as financial supports for travel, as they had to travel I believe it was five or six hours to go to these different appointments. And it also included rekindling his connection with South Dakota Services for the Deaf. This was really important as they had not had contact with him for about a year prior to seeing us. So he is now back on their radar and they are in connection with his caregivers. As important as the child, we also wanted to talk about caregiver mental health supports. As part of our plan, we made sure to touch on the mental health supports for Harry's caregivers by offering resources and supporting their mental health.

We talked about different counseling services, support groups, and we offered to make any referrals or appropriate connections to any professionals. So lastly, one of our



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goals for Harry was to establish a medical home. And we are still in the process for identifying an appropriate medical home for Harry, ensuring that he receives that consistent and coordinated care. This involves primarily having a PCP, and so we are still making sure that he's getting connection to those services to have that continuity and comprehensive support.

- Thank you so much, Jacynda. You know, you really make a point that sometimes in the care of our patients, we are the ones who see them more often than the primary care. Or sometimes they lose, you know, as they move. As you know, the transient of Dr. Messersmith's case showed, you know, it's really that, that oftentimes we would be that person that sometimes has to help coordinate that care. So thank you so much for that. So, all right, so now I'm gonna give my presentation on Shyloh. So I'm gonna tell you that I'm calling this patient Shyloh, because when I first saw them, they appeared very, very shy. So this person was 74 years old, and when I first met them, they were, you know, they came in, they were very reserved, very quiet, kind of hunched over.

When I sat in the chair, they sat up very, very, you know, put them in the chair in our room. They sat up very, very straight and were very nervous. It was very evident that the relationship that I would eventually establish with this patient was really, really needed in this case, because he definitely did not feel that kind of safety that I would often say our patients would need. So when I first saw him, he came in with RIC devices that had open domes and a low power receiver. He also had very, very small ear canals. So I will tell you that I ran the temps several times, because I was getting about a 0.4 ear canal volume bilaterally.

I was very perplexed by this and ran them several times making sure I was not up against the wall or things like that. And I was getting very, very small ear canals. So one of the things that he complained of is that his aide wouldn't go into his ears. And that then when they, if he got them in, they wouldn't stay in. And then he really wasn't



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perceiving any benefit. And so that's why we saw him. He was coming to us kind of as a last resort. I don't really know what to do, maybe you can help me. And so he was very nervous when he walked in. So I interviewed him, like I said, he sat up very, very straight in his chair.

He did report that he'd gotten these aids for free through a service that is provided here in the state of South Dakota. And so he really had attempted to go back, but didn't really feel that he was, he didn't wanna go keep going back, 'cause he felt that he was a burden on the system and that he should not be disappointed with the aids as they were a gift from the state and so therefore he shouldn't be complaining about them and he should just try and figure them out. So, that's why he came to us and he was very nervous that we were going to be judgmental or one that he know, he was complaining about these free aids or two, that we would be disappointed that he couldn't figure them out on his own.

When we did a hearing test, you can see here on the right that you know, he does have a sloping bilateral sensory neural hearing loss. Little bit worse than the right ear than the left. Word recognition performed at super thresholds, was a hundred percent bilaterally in our speech and noise testing did suggest that he had 8.5 db SNR loss in the left ear and a 15 and a half in the right ear. I don't know if he had previous medical clearance and that is something that I have requested from his medical records, but I'm assuming given that he was fit with hearing aids, that that medical clearance was obtained given the asymmetry. So this is the audio coming in.

And so I do wanna point out that once again, he was very, very nervous and very, very concerned. So what did this patient really want? He really wanted to know what he could do to make it better. He was taking it all on himself that he didn't know. So when I was talking with the patient, I wanted to establish what was his goal? Why was he here? And I kind of explained that his goal was he just wanted to be able to get them

into his ears and he wanted to get benefit, 'cause he felt that he was wearing them, but he wasn't really seeing any benefit if he could even get them in his ears at all.

And so really thinking about it, obviously we did a hearing test just to kind of see what our thresholds were. And as I was talking with this patient more and more and the student who was with me was actually doing most of the interviewing, you could watch the patient sit back and relax into that chair and it was very evident and the student actually commented on it later. Watching him relax throughout the appointment was absolutely astonishing, because as we were able to connect with this patient, we were able to demonstrate that we were here really just to help him. We watched them relax and really were able to connect with them on many different levels, whether that's where, how far his drive was in, the weather, things like that.

Just didn't always have to be about the hearing loss, but how we were there to help him. So what we found out is that he didn't really know how to use them. He really was just handed them the aids and the person had put the hearing aids into his ears and then he said, "Yep, that's how you put 'em in your ears." And then at least that's what the patient reported. And so, he felt like he didn't get the practice in the office to be, to really feel confident in putting them in. And then when he tried to to make follow-up appointments, he found making those follow-up appointments to be rather difficult, because the hearing aids were free and that provider was not getting paid as much because these hearing aids were free.

So after talking with this patient and really realizing what we needed to do, we came up with a plan and our plan was to do a hearing aid clean and check. These hearing aids were really good aids. I just took a picture of some receivers just for visualization. This is not necessarily the manufacturer that they were, but after looking at it, one of the things I pointed back was that his ear canals were so teeny tiny and curvy that that's why he couldn't get the hearing aids into his ears very well. I mean, I would've

struggled to get the ear, even small low power receiver in around this bend of his ear. And so what we talked about was that we were gonna do mold and into embedded receivers for insertion and retention so that we really didn't have to worry about, did he get it around the corner?

Is it gonna stay in? So you know, if it's molded then an embedded receiver, which we ended up having to do, because of the size of his ear canal, that at least he would be able to get them in and and keep them in. When I did connect the hearing aids to the computer to pull the audiogram off to see if his audiogram had changed at all, the aids were not programmed to them. The name on the hearing aids were offline patient. And so although I'm not, so I'm not quite sure if the audiogram that was in there was his, it appeared to be fairly similar to the one that I got. So I'm kind of assuming that it was.

And so luckily this was a product that we have used before. So I had the correct software, but when I connected the software, the software that was listed in the software listed the receiver as a moderate power and on his hearing aids were a low power receiver. And so you know, what's happening is that then that device is not getting the appropriate amount of electrical input from the hearing aid to drive that receiver, because it's going to be driven at a different level, because the receiver is going to be assumed to be a larger receiver since that's what the manufacture software thinks that it's pushing out. So that was a really big problem for me. And so what did I do?

You know, I clean, we cleaned them, we checked them, we appropriately fit them. And so then what could I, what could I do is, you know, billing for these. So when thinking about this is yes, what could I do, but also what could I bill for? And so we were able to clean and check these hearing aids and then we reprogram them. So in our clinic we actually have two different levels of hearing aid service. We have a basic hearing aid service, which is clean and check the hearing aids, run electroacoustic analysis and

ensure that the hearing aids are fit appropriately. We also have another level of service where it's if a patient comes in and their hearing aids are out of warranty, but they say something like, "Oh you know, my, I'd like to be able to hear better in this situation." or those things and we need to do programming changes.

After those hearing aids are out of warranty, you can build a secondary level of service and that's what we do. Additionally, we can bill for that electroacoustic analysis, which includes running the ANSI to determine if the hearing aid is meeting the specifications of the manufacturer. As well as we do run directional microphone performance, we run directional microphones and ANSI on every hearing aid that comes into our clinic, 'cause we wanna make sure that the hearing aids were meeting specifications and that directional microphones are working. As I talked about, this patient does have difficulty in speech and noise and one of the only things that we definitively know that can help someone in speech and noise is directional microphones.

So we always check our directional microphones. We do that on new hearing aids, repairs or any hearing aid that is new coming into our clinic. We also on this patient did some reprogramming, conformity evaluation or V50 20. We did a real measurements to ensure that these hearing aids were fit appropriately. So basically after we clean and check these hearing aids, we had an audio, we did a refit on this patient, so we refit them like they were new patients. And then we also did some education and training and you can bill for that as well. The education and training, we're teaching him how to use these hearing aids. We paired them to his cell phone, we taught him how to use them, we taught him how to insertion and removal.

That rehabilitative audiologic comprehensive care plan we offered to him, he could purchase that here, that was outside of his personal price range. But we do offer a rehabilitative care plan here where people can purchase a year of rehabilitative care, which includes all of these things that I've talked about. So that's how we do that here



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in our clinic. And so do know that once again we bill for our services and especially those real-ear measurements, even if things are free, patients want them to be able to work and so patients are willing to pay for them payment plans, things like that. So Shyloh I will say is no longer shy. And so, you know, now we do continually see him.

He's definitely part of our clinic care. He's actually referred a couple patients to us that are full pay patients. And so, you know, it actually providing those services to him and getting him to hear better really has generated more business for our clinic as well. And so I do wanna say that just because they're getting free hearing aids, their care should not be subpar. So if you don't feel like you can provide the highest quality care, just don't accept giving away those types of programs that provide hearing aids for free. So what's next for him? What's next for him is he is gonna actually use these hearing aids and we have a follow-up scheduled for him to come back and tell us the things that he likes or doesn't like about them.

I have seen him out in town and his smile is huge and he's just, you know, you can tell that he's actually wearing 'em, he's actually wearing them. And so that's something that I'm super excited about and those things. So I will say of course you couldn't go away without hearing me talk about real-ear measurements. And so, you know, real-ear measurements were really what drove me to fit this patient appropriately. He was not fit appropriately both by power of receiver and the piece in his ear. And once I did those, I really needed to redo those real-ear measurements, 'cause even if the hearing aid was originally programmed correctly by putting a mold on it, I definitely changed the venting structure of that sound.

And so I really needed to make sure I redid those real-ear. So when you're thinking about billing, that's one of the things then we think about. Do we bill for the mold and real-ear or how do we do that? And so we tend to structure it so that if we're changing those ventings, that that that real-ear is built somehow into into that billing. So thank

you all now we actually are going to, if you have any questions we'd love to hear them. I have a few questions for, and I'm sure we all have some questions for each other, so I'm gonna ask us all to come back on and you know, I know we all have a few few questions so you know, because I have control, I'm gonna actually ask Gabby a question first. You know, Gabby, was there a certain protocol that the CI audiologist and graduate clinician needed to follow when programming at the detention center? I'm really just curious about how that works.

- So I was actually the graduate clinician that went to the facility with one of our CI audiologists here. And for this appointment we had a specific list of things we could and could not bring. So for example, we could not bring a pen or pencil within the facility. So you can imagine that kind of makes a little bit of complexity, like taking notes during the appointment. So me and the audiologist that were there, we really were able to talk through the case after we concluded that appointment and then wrote everything down, 'cause that was one of the things we could not bring in. So for the equipment that we brought to this appointment, it included a computer with Noel Inquire List, the upgraded equipments with that CI, the parts and pieces.

We had one singular piece of paper. I remember on my list for the appointment I had piece of paper and that on that piece of paper we had the previous programming parameters for this device as we did not have access to internet or an ethernet port in the space we were provided. So we had to manually enter in everything on the programming software. And then we also brought in one autoscope with one otoscopy tip. Those were the ones that I really remember. And basically whatever we brought in with the exception of like the device, the batteries, chargers, we had to make sure it came back with us. And in that appointment, one really unique thing is that it was the patient, we had a guard outside of the nurse's office that we were in and then the case manager/social worker for this patient and he's the person in that facility that works one-on-one with our patient.

So we actually kind of included him on our discussion of parts and pieces, parts and pieces, care and maintenance as this patient I think was one of the first ones in this specific facility that had a hearing device, specifically a CI. So we basically were able to talk through all of the different care and maintenance things as our patient was not allowed to have extra batteries, the chargers and other things like that within his own area in the facility. So yeah, we like Dr. Phelan and Jacynda mentioned we were doing audiology in non-traditional spaces. So it was a really interesting experience to be a part of.

- Amazing, so, you know, Jen, I have a question for you. So, you know, sometimes you have a limited amount of time with kids. What do you do, you know, what information do you need to be able to move forward?

- So the thing about working with kids is, I don't think about it as one and done. And I think sometimes we might give a family or caregivers this idea that they're gonna have an audiology appointment and it'll be this one appointment. Really, it's taking bits and pieces and it's filling in the gaps, but we need to know it's putting things in order of importance. So if I'm gonna get a little bit more information, I wanna be sure I'm getting the information that means that I can move forward if I need to, if there is a hearing loss present. So that's the critical information and then we build in from there. So my goal isn't to get everything on the first visit, you know, being where we were, we had all of that time, but really it's taking the time you have and having things that are most important so that if you need an intervention, if we need a treatment, we can start moving on that treatment even without the full picture.

And that's really key. I have a question, I have a question for Rachel. So you know, universal healthcare offered in the UK, I didn't realize there'd be as much need for private pay audiologists and clearly that's not the case, so I appreciate you talking

about it. What are some of, what are your thoughts or experiences, why do you feel like people would pay for the devices when they could get them for free?

- Yeah, that's a really great question. And you know what, that was also something that I hadn't realized before I went over there. And so actually before I went over to the UK it was right before over-the-counter devices in the US had come out. And so, you know, I remember having conversations with my classmates about how to approach that with a patient and why would they come see an audiologist versus just buy the devices over the counter. And so then when I arrived in the UK, I got the whole rundown on the NHS and from my experience over there, I've really seen it boil down to the care. Patients are happy to pay for the really clear and concise follow-up, the consistent follow up, the readily available need that they can come, they can bring their devices if an adjustment needs to be made, if they need the tubing on their ear mold change, I mean I think they're really paying for the convenience and kind of just also the genuine care that we all have as audiologists and I think as long as we portray that and you know, do things to the best of our abilities and follow evidence-based practices, I think that that's at least the experience that I had had given the placement that I was at. I have a question now for actually for Dr. Messersmith. So I'm not one that works with children on a daily basis, but so how do you get a younger child or even a toddler to sit through the ESRT tests and then what do you do if you can't get a stable baseline to record for that test as well?

- Those are good questions Rachel. I get those a lot from people who maybe don't work with cochlear implants quite as often. And in our clinic, I think this is even more so relevant because we do ESRT so early in their device usage, right? So we usually do ESRT for kids in initial activation or soon after. And for even adults we do that usually like within the first week to one month of device use. So we do it really early. So when we're fitting kids, they can be babies, they can be toddlers and we're checking this and

really, I always say like being a pediatric audiologist, you have lots of tools in your repertoire, right, that you can pull out.

We have books, we have stacking blocks, right? With ESRT when we pick that entertainment item, we have to keep in mind that what we're measuring is a myogenic response, a muscle response. So whatever we're using to entertain them needs to have minimal muscle movements. So one of the best ways honestly find an iPad, right? Like, and I know that's like obvious, but talk with the parents or the caregiver, find out what the kid's favorite show is, and this maybe sounds extreme, but I often talk with parents and find out what that favorite show is in advance and then ask the parents if maybe they cannot let their kid watch that particular show for a day or two building up to the appointment so that they're extra excited to see it.

And then when it comes on, they like almost go into a trance and it really tends to work really smooth. Some of my other tricks that I use are mirrors or making faces at them. Young kids really like faces and I have this hidden talent of stacking blocks and rings on my head being able to balance them quite high and that really puzzles most little kids and they can't figure out how I have that magic touch to be able to do that. Another trick, if you're having a hard time getting a stable baseline, I find it useful to have the person swallow, right? Like if it's a child who has a bottle or a sippy cup or they're using a glass of water, just have 'em take a sip of water and just that swallowing reflex can kind of open up that eustachian tube and settle down movement a little bit and really can help you to get a stable baseline for a period of time after that.

We're running outta time, but I have a question too that I wanna ask and so while I have the mic I'm gonna do so. So Jacynda with that case now, I think it's really important to think about the adjustments that you may have needed to make when you were testing that kid, right? Thinking of the various facets that made that individual

who they were, what did you need to modify to be able to get your assessment completed and get meaningful results?

- Yeah, so that started when they first walked in the door. So we wanted to make sure that we were talking directly to our patients. So we got down on their level, introduced ourselves and made sure that they started that interaction off on a comfortable note. In the booth, a couple of different things that we had to employ. Our patient couldn't raise their hand or tell us when they were hearing the beep. And so we had to learn how to read those non-verbal cues. For example, Harry had those eye widening and then halfway through he actually turned to have his responses turning his head. So we had to be a bit, or able to adapt to understand what his responses were to make sure that they were reliable in what we were reading.

- Fantastic, everyone. I really appreciate everybody and your questions and things like that. You know, I wanna kind of wrap up and say, you know, that this, we appreciate everybody here coming. This is the point out of all the different things, you know, we definitely pointed out the continued need for watching kids as they, if they are more transient, we wanna make sure that people get the follow up and the care that they need, then that's why people come to us. You know, that is why OTCs are not gonna completely disrupt our entire field. You know, that oftentimes that we can catch some of those behavioral things or catch them earlier if we have the input. And so hopefully we could keep people outta that prison pipeline.

We definitely talked about the importance of new born hearing screening. And that loss to follow up. You know, Dr. Messersmith and the JCIH definitely are happy that we're doing that. But even in Guatemala we can do that. Family support is definitely important and sometimes it's hard to figure out who to include in that, but sometimes we are the stable person for those kiddos and the quality of care that we provide all of our patients should be equal. They deserve our care no matter how they paid for those

devices. So, you know, I think that that kind of wraps up our session for today. I hope that everyone does real-ear. That's where I'm gonna end this. And you know, I do think that here in South Dakota as well as everywhere, our patients definitely deserve the quality care that we all on here and everyone of you definitely provide. Thank you so much.



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