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3/5/19

9:40-10:05 A.M. CT

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>> Good morning!

My name is Michelle Graham. I am with St. Joseph institute for the deaf in St. Louis. And I am the lead early interventionist with our program, a listening and spoken language specialist. I'm here today with Liz Welch, our audiology, and we're just going to talk about what we've kind of been doing in our program as far as serving the audiological needs of our children who are presenting with additional diagnoses to their hearing loss.

And how we're kind of working through that process with them from the time of diagnosis through transitioning out of their program.

So at St. Joe's, we have been around since 1837, a very long time standing organization. We are providing listening and spoken language services currently in St. Louis. We have an EI program, so birth through three working with the Missouri First Steps System. Our service provision is going through that, therapy and audiology. They are receiving hearing aids, monthly audiological visits, counseling, batteries, earmolds, whatever, you name it.

Cochlear implants, that's going through the medical providers, but we're still able to provide testing services.

And then we're also doing tele‑therapy. In addition to seeing families in St. Louis, I'm providing tele‑therapy sessions. We have several therapists reaching out internationally to families and school districts working with them and providing those services.

So right now our early intervention population... just looking at the zero to three children that are in St. Louis, in our St. Louis program, 46% of our current enrollment is presenting with an additional diagnosis in addition to their hearing loss. And that's been kind of a consistent number the last couple of years, and so when we're thinking about that and how we can, as therapists and as audiologists work with families to really kind of align our services so we're best meeting those needs for those children and those families. And how do we start to kind of think outside the box and maybe not follow our traditional patterns of service provision and think about how to really individualize.

And then the collaboration piece. Our families are coming in for audiology testing sessions, counseling sessions, once a month. And having them in the booth, the therapist in the booth with this family. And it's a nice collaboration because I'm able to work on some things at home with the family that then we can carry over and tie into those testing sessions, and I can give Liz some information anecdotally, observation, hey, here is what we're working on at home, they really love this song, if you're going to do speech stuff, or even to gain attention, let's tie this in a little bit. Or what comes from the testing session, then when I'm out in the family's home, then I can kind of relay that information while I'm out in the home and have that thorough, seamless therapy where it's very family‑centered and family‑driven, and then collaborating with the medical professionals.

So Liz is going to talk with you a little more about what that would look like when they're coming in for audiology.

>> LIZ WELCH: Hi, everybody!

So, like Michelle said, we spent a lot of time collaborating, and collaborating with not just other professionals, but with the family themselves to make sure we're meeting their needs. And I've heard that in all the sessions I've been at this week, there's a lot of talk about meeting the families' needs, not but what we want to professionally attain or document, but what does the family need out of this service we're providing.

So we initially are developing a tailored approach for each family. We get the ABR findings from the hospital and I may or may not have all four of the frequencies that they can test for each ear. I might have one frequency here and one frequency there. And then if I have a multiply involved child, it might be because it's difficult to test. How am I going to attain all that other information? I have to determine almost immediately whether or not we're going to do a trial with loaner hearing aids to see if, hey, is this kid meant for more of a bone conduction aid or for a behind‑the‑ear hearing aid, maybe they need a trial with another system when they get older, or do we know exactly what they need and we're ready to go to a personal set of hearing aids and obtain those through the state.

Then we're consulting with the ear, nose and throat doctors, neurology, any of those professionals that might be involved with this child's case. Because I want to know if they have any health issues that may impact the way we are delivering our services, both as far as assessment and then as far as in the home. A lot of times there will be sessions that the therapists are providing when they go to the home that are in tandem with a vision specialist, an OT, a PT. What do the exercises look like they're doing, and how might the equipment might be in the way of those things. So I'm consulting with all of them to look at all the different aspects that make up this child's situation.

Then I try to develop a way to consistently test them in a modified manner.

The number‑one thing I've learned at working ‑‑ excuse me ‑‑ while working at St. Joe's is not to make assumptions about any child's ability. So you can bring a child to me that someone may consider a severely impaired physically, and I'll say, okay, well, what can they do?

What is it that they are able to do?

There's got to be something. And we're going to try and bank on that one thing, expand on that, and make that the way that we successfully assess them.

And the way that I do that is by collaborating with the OT, PT, visual therapist, and the deaf educators, to determine their strengths and their challenges. So, again, back to those health concerns, and then I'm really looking at physical limitations.

So how do they respond to sound and how do we capitalize on it?

How many audiologists do we have in the room? Anybody? Lots of you.

And parents?

Okay, a few parents. Good.

So, you guys know that there is ‑‑ there are very small responses. It could be something as simple as an eyebrow raise. So a child who maybe can't lift a ring to their ear and listen for the beep and put it on can still convey that they've heard something to you in a very subtle way. So I try to hone in on, what is the subtle way this child is going to show me?

Once we determine what that is, I'm going to provide intervention and treatment while assessing. I have them come in every month. That is possible through our state ‑‑ Missouri First Steps Program will pay for them to come once a month to see me. So I'm able to really develop these listening skills in kids where it may be difficult if you're only seeing them once every three months or six months. They aren't used to doing the VRA tasks or play tasks and they really need some practice doing it.

So we do have that advantage.

And then I use the findings to guide our future intervention strategies and listening therapies.

So how can we build in this strength everywhere else? They're doing it in therapy and bringing it into audiology, and we're trying to build on top of those skills.

Just a quick review for the parents in the room. The different types of behavioral testing that we do, I won't spend too much time on it, but behavioral observation, like I said, is where you see an eyebrow raise or maybe the child just shifts their eyes in the direction of the sound, something like that, or maybe they're sucking on a bottle, a pause in breath.

And then VRA is where they're turning to look for the sounds. And then there's a reinforcer, either a motorized toy, or we use video reinforcement, so we have screens on either side that they look for. And conditioned play is where we incorporate a task. Maybe listening with a ring or a block or putting a ball in a bucket. Then there's so many variations on that as well.

So these are things that I have determined or decided to call it "response limiting factors." Things that we may come across that make it difficult to test kiddos. These are things in school but nobody tells you how to handle it when it shows up in your booth. You get a kid and they say, well, he doesn't have really good vision. He can't see.

Okay, how are you going to do VRA? How are you going to do Conditioned Play Audiometry? You have to get around those things if at all possible.

I've listed things I've come across that have limited viability to test. I've been able to overcome many of them. Just with simple things. That's what we we'll talk about today.

I'm trying to look and see if these things need special mention.

So the breathing and suction equipment, we have a lot of kids that have to be suctioned all the time and you have to be patient with the family and say "you do what you need, take as much time as you need."

But they're very noisy, so that's why I put that in here. We had a kid who had to be hooked up to ventilation equipment all the time. So how was I going to test him? He had a slight to mild hearing loss, so I was getting down to 20‑decibels and his equipment is probably at 40 or 50‑decibels. How do I test this kid? I can't unhook him. We were able to manage to set the equipment right outside the door, and I was still able to get a good test result from him.

So little things like that.

And then level of consciousness. I have a lot of kids that are not very alert but can still show us what they're hearing to some extent.

So some simple modifications that I have been successful with for vision and then some motor concerns as well. Reducing or altering the lighting in the booth. I have kids where I have to flat‑out turn off the lights. And for them, if I turn off the lights and then I have my VRA screen light up, perhaps we use a tablet, I mention that in here several times, they're able to zero in on that light from that screen so much easier if I don't have that glaring overhead light right on top of them.

So something that simple.

I have movable video reinforcers. They're screens, but they're on an arm, so I'm able to pull them away from the wall and tilt and adjust them so they're at a better angle for that child.

And then if that doesn't work, we have kids that can't get close enough. I need them under that centered position in the booth, so I can't move the chair over towards the screen to get them close enough, but maybe their vision is right here. We've started incorporating tablets for that, bringing in an iPad and using that as a reinforcer as well.

I have children who maybe have cortical visual impairment, so we're not sure exactly what they see, especially at this age. They've often done very little testing, enough to know there's a problem but we don't know what or if they see. We've experimented with different colors that light on the tablets. We don't have control over VRA. Those are just cartoons that pop up. But we have had children that respond better to different colors, different textures... or patterns.

And then tactile for people with visual problems, maybe they cannot ‑‑ they have no vision whatsoever, maybe they need a tactile reinforcement. I had a little girl who would smile when she knew she was about to be tickled. So the audiologist at the time ‑‑ I was an extern at the time, but the audiologist would say... one... two... three!

Because that's what her parents always said at home when they were getting ready to tickle her. She knew in anticipation of that she would start to smile, we knew she heard it and I would give the tickle. There are other versions we've done. You can use a bone oscillator even if they felt that felt funny or silly.

And then for motor, using the movable video reinforcers again. If they're not able to turn their head completely, having that screen there so they can see. And then the tablet as well, moving it into their range so they can see it.

And then we've used different apps, just really anything the child is interested, maybe a familiar app they use at home, but bringing that and using that for the conditioned play process. I had children that had, you know, malformed digits or maybe don't have a hand, maybe two fingers. They can't hold the toys to do the play task, but they can do a touch screen pretty easily. You can have a game such as Tic‑tac‑toe and they can do that and respond in that manner.

Also allowing lots of time for motor planning with these kids. I see children with incredibly delayed responses, I think more so than most of us realize, we need to take our time.

That brings us to our first case study. We had a picture of this child earlier in the presentation. This was really an amazing family that was very involved in caring for their child and meeting all of her needs.

Just a little background on her...

She came to me at five months old. She failed her newborn hearing screening. She had an emergency ‑‑ her mother had an emergency Caesarian at 24 weeks, so she was very sick. She was in the NICU for four months with a ventilator and ototoxic meds. She had hemorrhage and retinopathy prematurity. Her vision was compromised as well.

They suspected ANSD on the ABR, but they were able to get some waveforms with fairly poor morphology. They had a severe loss for the right ear and severe to profound for the left. I will tell you the only frequency they gave me was 500‑hertz. That was it.

So I'm supposed to program equipment based off of that (chuckling).

And so the first thing we did... and I see Bev is here. The first thing we did was get her in the booth. This mother was very frightened by the prospect of cochlear implants, which had been recommended immediately. And she wasn't ready to talk about that, and that was exactly what she said to me, I'm not ready to talk about that right now. And I said, okay can let's do some testing. We have a year to think about that anyway, I think.

So we just started with testing. We got her in the booth and sure enough, the parents reported they were seeing responses at home, and we recorded responses in the booth in the moderate range for both ears. So I did not slap a full gain hearing aid on her immediately. We took our time.

For her, the response limiting factors for forehead and muscle control, obviously as she got a little older, she couldn't hold her head up fully or turn very quickly. She had limited vision, really significant response delay, the most I had seen. And she really did not like her ears being touched. So we always did otoscopy and tympanometry at the end of the appointment. That's another tip. You feel like you're flying blind for a bit, but it's worth it. We weren't sure what the cognitive capacity was, too, with all the traumatic events.

So she came to me for her first visit in February. A few months after her ABR. I think the parents were mulling things over and getting settled. We got the responses in the mild to moderate range. Programmed the hearing aids conservatively. And we continued testing. We had days we would get good responses but it was with fair reliability.

And some of this I'm going to now blame on myself, not knowing the timing she required to respond.

They worked at home significantly with her therapist and with visual therapists on building her skills to attend to sound, to look for sound, to really pay attention to it, and when they did that, they were, you know, giving her the stimulus and really waiting and watching for that response. Think about how long a parent might watch for that to happen. And they would come to me at the monthly appointments and say... Liz, she hears, she hears, she hears!

I say, I'm not measuring it in the booth. So one day I knew they were working hard, so I decided to just slow myself down. So we identified her strengths as being this... head turn toward the sound with significant delay. She would vocalize in response to sound which we would see infrequently, but it did happen. She had better vision with the bright screen in a dark environment. She was the first one I incorporated an iPad with. It was helpful. She use the Peek‑a‑boo barn app. And ability to pick pictures of family also with significant delay.

It took a long time.

What is a long time? I encountered the one day, out of options, they wouldn't get another ABR but they swore she could hear. So I decided to count Mississippis. And I got up to every time 4 Mississippi... if you count 4 Mississippi in your head, that is an incredibly long time in audiology where we're going beep... he heard it... beep... he heard it...

I had to challenge myself, slow down and watch. When I did that, in fact, her responses were consistent.

So we began using some of the strengths and allowing her to turn to the tap let and then towards the end there we were having them ‑‑ they were able to identify some single syllable words that were fairly similar.

I don't know if I have those listed or not.

They were ball, book, bus, pictures of families. She could do mama, papa, nani and nanu were grandma and grandpa.

That gave me an idea of the ability to discriminate. It wasn't a discriminate list but it worked for her.

They did eventually have a second ABR and confirmed the hearing had in fact come up to the moderate range. We continued with VRA and she started to refuse her hearing aids quite a bit. She would not wear them. We supported the family and tried to be encouraging, but ultimately she really would not wear them. So we did more testing, more testing. She was getting better, better at this VRA response and I was able to test her down to at least 25‑decibels across the frequency range. So she had thresholds at 25, and I would consider these to be minimal response levels. So I don't think she's telling me the very softest thing that she can hear. But 25 was definitely audible.

At that point the family was interested in doing a trial without hearing aids. We reviewed the risks involved with ANSD and fluctuations and quality of hearing. But ultimately they decided that they wanted to try it without hearing aids. She did continue to make progress and things went well the remainder of the time she was in the program. I have not heard from them since and I should touch base because I would like to hear where she is today. But that was an interesting case for me. I learned a lot from that. How much time do we have left? Five minutes.

I have one more case I'll try to go through briefly and if anyone has questions, you can approach me afterwards.

This second one came to me at one month. He has a very rare genetic disorder, so much so I didn't list what it was. He has a degenerative neurological condition. Dysmorphic features. His head is malformed and he required a helmet for a period of time. Stenotic canals, small... it's not microtia, but his eyes are so tiny. I should have brought his earmold in. It's the smallest one I've ever seen.

Cortical vision impairment. ABR came back with 50‑55‑decibel loss in both ears, and because of his condition they presumed it would be a progressive loss. They couldn't promise in other cases they had had.

So they did receive a second ABR at four months, which showed that his hearing had shifted into the moderate range. And for him I will say when he first came to me as small as his ears were I could not get a sufficient earmold impression on him. I could not amplify right away. We couldn't confirm whether his hearing was here or there.

So I was kind of flying blind. We did start with a bone conduction aid since I couldn't get sound in the canal. That was a little bit cumbersome.

His response limiting factors, he was not good at taking a bottle. So I couldn't do traditional VOA with him with confidence. He had poor head and muscle control. He leans his head to the right due to the shape of his head, he lays on that side, which made it difficult for, one, a head turn, and, two, to position an insert in the ear.

Limbed vision, delayed response and unknown cognition for him as well.

So I couldn't accommodate the earmold. He had a helmet. A helmet and bone conduction aid are not friends. They are not friends!

I had a man this year tell me that he made helmets and he said, oh, yeah, sure, we can accommodate that. I will cut a place so we have the forehead placement and he called me and said, no, it's not going to work. Yeah, I didn't think so. But he tried. He tried.

So they were concerned that his hearing had reduced by the age of 12 months and that's when they decided to... I think... I can't remember if it was the second ABR or third. I think that's when we had the third.

So we had varied reliability with his testing. Family was working, again, diligently with him at home. I'm going to wrap up here.

And I will show you on the next one, he, again, did well with bright screens. He really loves the color pink. We changed the lock screen on the iPad to be pink. So when you push the button, it shows up locked but pink and we would flash that in front of him and he would be drawn to it and look at that. So something that simple worked for him.

If you look here, I did eventually get a full behavioral eval on him and he, in fact, had a shift in hearing. My minimum response levels are at the top. And he obtained an ABR with, I believe, a second set of tubes down at the bottom. So you can see, he was still within 10 or 15 for the most part. 4000 is a little off. But we were able to validate what the parents were seeing.

So I'll move to my summary and we have to get out of here.

The input you can obtain from the other professionals that you're working with and from the family and designing the way you test kids is invaluable. It has really changed the way I do things, just listening and incorporating that.

Try to think beyond what usually works for you, that drawer full of toys you have, try not to think about them. Ask the family what toys they have at home and the child might be more responsive to.

What can you interpret from what you obtained? You might not have a standard speech score of some kind. You don't have a PBK with a score. But you have something that shows the parent validates what the parents are seeing and validates to the extent you can what you program the hearing aids to do. And so you can comment on that at least.

And then I think it's really important to allow the parents to take an active role in the assessment process. I think when you have these children that are multiply involved, they are just so sick and they have so many appointments with tough news, discouraging news, and this is a way to feel they have a little control and that they're helping the process along and we can make as big a difference as possible this way.

That's all that I have. Thank you guys for coming.

[Applause]