ROUGHLY EDITED COPY

EHDI

Mineral D/E

1‑3‑6 Enhancement through Services at Schools for the Deaf

Casey Judd

3:00-3:30p MT

March 20, 2018

CART/CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

[WWW.CAPTIONFAMILY.COM](http://WWW.CAPTIONFAMILY.COM)

 "This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings."

 >> Good afternoon, everyone, let's get started with our projection. We have Michelle Bode and Jennifer Mertes with us. Enjoy your presentation.

>> Thank you so much for coming. We're pumped to share the things happening in Maryland. Born and raised in Maryland, we're excited to share things we're working on. Particularly about the enhancing the 1‑3‑6 model by offering services through our school. This is what we're going to talk about today.

 When we first started thinking about providing follow‑up to newborn hearing screening services, we were curious what other programs were doing the same? We did a survey for education programs across U.S. We talked about how we establish our centers. Feedback we received from families and considerations for the future.

 So... just a little about us. I'm Jen Mertes, I'm an audiologist at Columbia campus.

 >> I'm Michelle Bode at the Frederick campus.

 >> We're fortunate to have two campuses, we have some interesting geography. The state is small, but it's oddly shaped and takes a long time to get just about anywhere. So... you can see on here and all I have is a little pointer. Columbia is here. Michelle grew up in Hagerstown, up here. I grew up in Waldorf.

 One fun fact about Maryland, we'll give you a lot of facts about Maryland today. Maryland and Virginia donated land to create our capital. That's why it's almost a perfect square. We'll share more fun things about Maryland with you as we go through.

 >> Hopefully by now in the couple days, you learned what the 1‑3‑6 national goal is. It's to have your newborn hearing screened by 1 month of age, confirm hearing status by 3 months of age and if a child is identified with a permanent hearing status that could affect language acquisition, to enroll in early intervention by 6 months of age.

 So... in audiology, we have three different levels of this hearing test. In initial screenings, that's usually what the baby will get in the hospital, that's a level one test. A level two test would be for a baby who wasn't screened in the hospital or maybe referred that screening, they'd come see us for an out‑patient screening.

 And level three diagnostic test is the full ABR. If a baby is coming for a level one screen, maybe they were born in a birthing center, need that level one screen. If we had to do a full diagnostic ABR, we can do that in that appointment.

 >> So a little about the survey. We were wondering what other Schools for the Deaf were offering the service? Were we unique? If there are others doing this, can they help us get our center off the ground running with common practices?

 We created a simple survey using Google forms and asking simple questions about what audiology services do you provide at your school? We were able to get a list of Deaf Education programs off the website and we, it took some time to find e‑mails for each audiologist, I can comment on websites from different schools, but it was a challenge. We got 99 contacts where we sent the surveys out to ask about audiology services. We had a high response rate. 76% responded and gave information about their program. Of the 76 schools that replied, there were 56 that had a dedicated audiologist position. At least one.

 There were 16 programs that did not employ an audiologist, which was surprising for us. Some of them did indicate that they contract services out when needed, but I guess because we were audiologists, we were surprised a program dedicated to deaf and hard of hearing children wouldn't employ an audiologist, but it happens and there were four Schools for the Deaf that had vacant positions, but for those, we were able to connect with the audiologists who retired and moved on and they answered on behalf of the school.

 There were 23 programs that did not participate in the survey. They were a combination of public school programs, private programs, and Schools for the Deaf.

 So... our information today doesn't reflect 23 of the schools.

 For the responses, we found out we are, in fact, unique. There were, including us, six Schools for the Deaf who offer the service across the U.S. And... I'm maybe making an assumption, I think if you were a school that did offer the services, you would have replied. I ‑‑ so, six Schools for the Deaf and three private programs that specialize in working with children who are deaf and hard of hearing. Those programs, we asked how many babies do you see per month? A big range between one baby a month to 25 babies a month. We didn't ask the question looking at their websites, it's probably correlated to how many audiologists they employ. At MSD, we block one morning a week on each campus. So... essentially two appointments each week. For, to offer families. We try to see two babies a week. How many are actually identified as deaf or hard of hearing was another question? The other programs estimated between 5 and 10%. Why do you think we'd have a higher percentage of babies identifying as deaf or hard of hearing?

 >> [Too far from mic].

 >> Is it because we have more families that are deaf or hard of hearing that might bring their own kids here? Hopefully we're not just fluffing enrollment, right? These are really babies that are deaf or hard of hearing? I'm just kidding, that's a bad joke. But you're right, Maryland has a higher population in general of deaf and hard of hearing individuals. It's not a surprise, we're close in proximity to Gallaudet, close proximity to a lot of government jobs. The government does employ many deaf and hard of hearing individuals.

 Frederick, Maryland, specifically is you know... famous in the deaf world, there are deaf families that move to Frederick, Maryland, so... that they can enroll their children in MSD. We do have a higher population of deaf parents in our areas. And that doesn't mean they all have deaf babies, okay? There are many deaf adults that also have hearing babies and so... we see all of them.

 Okay... and... I mean, who hasn't heard of a Maryland blue crab, right? Delicious. Is there anyone in this room that hasn't eaten it? You need to. If you haven't ‑‑ make sure it's a Maryland crab. It can't just be any crab from Louisiana or another state or North Carolina, blue crabs are different.

 So... and Old Bay... delicious. Not just for crabs. You can put it on popcorn, French fries, chicken... we contacted Old Bay and they were going to send samples for today, but they haven't arrived. I don't know what happened, but we were hoping to hook you up.

 So... we want to just let you know how we established the centers. We applied for a grant in 2014 and then the two of us and our third audiologist have to be trained in doing infant ABRs. It's a skill set, not every audiologist comes out of school as an expert.

 We had to market across the state of Maryland, let the birthing centers know the service is available. And we launched in 2015.

 So... we set up a Memorandum of Understanding between the Maryland School for the Deaf and the Maryland Department of Health with two goals in mind. With anything else, the biggest barrier tends to be cost. We wanted to provide a free service. We wanted, no matter where somebody lived in the state, them to be able to have easy access to our centers. Both of our schools are off the highway. There's free parking, we're a convenient location. The first school was to avoid those geographic and costly barriers.

 And then, the second goal was to be able to support the families after they've been identified as deaf or hard of hearing. If they choose to get hearing aids for their children, they wanted to have those hearing aids there and ready to go and we can also use those hearing aids as hearing aids in our school for our current students.

 So... up until January of this year, we have seen, in the last three years, 138 babies. That was a huge surprise for us, we didn't think that we would see so many babies. So... we've had 161 appointments and... the reason that some of the kids have to come back for a second appointment, they maybe woke up in the middle of the study, in the middle of the test, they may have had fluid in their ear and had to come back for a second test. Things like that, there were 23 babies that came back a second time.

 Of those 138, we identified 42 as deaf or hard of hearing. There's that 30%. 60 babies that we were going to see, we knew we were going to do level three diagnostic test immediately. Either they had deaf or hard of hearing family members or other risk factors, Down Syndrome, maybe they were premature.

 Out of the 42 babies we identified as deaf or hard of hearing, 28 have enrolled at Maryland School for the Deaf. We're really proud of that. We do tend to see that the babies identified as deaf enroll right away, but our school is open to hard of hearing children as well. So... Maryland is a unique, multiple‑service provider state so... if a baby's born and we refer to the county and they start to get infants and toddlers services, they can still get MSD services as well. We can go out for home visits, they can be involved in the Parent‑Infant Program, again... we're proud of that number, 28.

 So... just to show you out of the 138 babies we've seen, 63% [breaking up] 17% are deaf. 13% are hard of hearing. 4% have the conductive component with a normal bone line, so we'd expect, eventually that they're probably hearing and only two babies that we've seen, we've had to review out for a sedated ABR. That's a number we're proud of. If a baby comes in for the first time at three months old and they have to come back two months later, they probably won't sleep. The earlier that we're seeing these babies and identifying them, we are saving them from having to go through that sedation.

 >> And here are some ‑‑ if you're thinking about the Maryland EHDI program, in general, over the years, they report 80 to 100 babies identified as deaf or hard of hearing in Maryland each year. We looked at Maryland School for the Deaf each year we've been running. Each year we identified 14 to 15 babies and we looked at thinking about the 1‑3‑6 model, how are we doing with the age of the baby when we see them? We started off not so bad. The first year, 2015, the babies tended to be about 11 weeks old at the first appointment. Which is meeting the goal if you're able to identify them in that first appointment. If we had to reschedule, we'd be missing the goal. As you can see, when we get down to 2017, we've got that down to about 8.5 weeks. That was exciting to see.

 We also looked at you know, how long does it take parents to get an appointment? We think we're able to accommodate families much faster than a hospital or a clinic, but we wanted to see if we were right. It looks like the average time from call to appointment is about 12 days and that is ‑‑ we didn't take out any outliers or anything. An average 12 days. There's some we get in very soon and some have to wait a week or two. But... we think that's ‑‑ we're thinking that's much faster than any clinic can do.

 All right... so, what do we do after identification? If we have a family with a baby, who is deaf or hard of hearing, how do we handle that appointment? What we definitely learned over time is that you really can't have any preconceived notions about how that appointment is going to go. We all hear the ‑‑ I don't ‑‑ myths of, you know... deaf parents will celebrate a deaf baby or... hearing parents will grieve a deaf baby. What we found is that is not always the case. There may be a hearing parent that doesn't show any grief at that time and is ready to take on the next step and learn more. We've had deaf parents who were hoping for a hearing baby, for a variety of reasons, so... we've really learned to just go into it to collect the information, present it in a factual manner and wait for the family to lead where it goes. We don't... you know... jump forward and think we know what the family needs. We wait and have them tell us what they need.

 If they happen to be open to receiving services from a School for the Deaf, we are ready. We are staffed with every profession you can think of that specializes in working with deaf and hard of hearing children and their families. If they need behavioral support, mental health support, definitely audiology, even in our state, sometimes it can be hard to find a good Pediatric audiologist. We work with deaf and hard of hearing children every day. So... we can offer hearing aid services, behavioral testing, we had Deaf Educators, free ASL classes, we try to support them in any way we can. And... again, we can do that in tandem with the county programs. They don't have to choose, and... our early childhood is for any modality. It doesn't have to be American Sign Language, if that family is choosing spoken English, we'll support that choice and we'll be ready if they're interested in learning sign language, but... it the really more about raising a deaf and hard of hearing child, not particularly about ASL for those early years. Hopkins, right? I mean, it is a world renowned hospital and we have it right in Baltimore. It's another reason why Maryland's awesome.

 Did you know the naval academy was established in the 1800s in Annapolis? Go Navy and we're home to the Preakness. Maryland has something for everyone. You should come visit us.

 >> We wanted to ask all families what they thought of our services? We had 27 families out of the 138 respond to our survey. We decided that 27 families while they were taking care of a brand new baby could respond to a survey. We thank those parents who responded. 100% of the people were happy was the appointment time. Quick appointment time, they were pleased with. Most said our staff was friendly from the second they walked into the door for their appointment. They appreciated the quality of services, they got their test questions answered and all but one would recommend MSD to other families for that ABR service. I want to touch on that really quickly. If you had an ABR for your own child or an audiologist that does ABRs, when you're testing a hearing that was deaf, the test goes by quickly. It can take a couple hours to find out exactly what this baby was hearing. That was the case with this family. I think they thought we didn't know what we were doing because it was taking so long, but their baby was hard of hearing.

 >> We have a short video of two parents. [No sound].

 >> So cute.

 >> So... almost all of the people who replied to the survey... [no sound]. ... we'll watch about her later, I guess.

 >> Technical difficulties.

 >> So almost everyone replied they were most excited about the free service. Who doesn't want a free service? And we have free parking which is huge too. If you're going to the city and going to a hospital, you're going to pay for parking and then carry your stroller and baby carrier across the city. It's convenient. A lot of people responded the audiologist could sign with them. We are culturally sensitive. We use that sensitive language with the families. People said they were happy with the appointment time and some people just came to MSD because the hospital or the flyer they got from Maryland EHDI listed our name as a recommendation.

 And we just wanted to show you, quickly, our two centers, Frederick's on the left, Columbia on the right. We have a comfortable chair, dim the lights, whatever we need to make the family comfortable. We're not rushing people through their appointment. If the baby gets there and is awake and the parent needs to feed the baby to get them to sleep, we walk out and they do whatever they can to get the baby ready for us.

 >> All right... so we've been sharing with you a lot of great things today about our centers and what we've experienced so far, so... we had those listed on what we'd like to continue when we're thinking about the future and one of that is even ‑‑ we've seen this as a great outreach opportunity, even though most of the families that we've seen had hearing babies, those were families that have left Maryland School for the Deaf with a positive feeling. A positive experience and they've met deaf people, you know... when they come into our building and check in at the front desk, our, you know... front desk person is deaf herself. And they see deaf people in the hallway. Living regular lives and... a lot of parents have commented on how nice it was to come and see that the School for the Deaf is just a regular school, like any other school that could be in their neighborhood. And those families can potentially share the great experience that they had with other families they pass or meet in the future.

 One ‑‑ we have faced some challenges and... like, most challenges we hear about involve money and time. So... the free service is great, but if the family doesn't use American Sign Language or if they don't speak English, we, then, provide a foreign language interpreter.

 And... again, these appointments can be lengthy, they can be two hours, or more, because we ‑‑ we also use a language line if our interpreter shows up late or has to leave early or can't extend the stay. Again... if that family needs an extended counseling time, we'll stay with them for as long as they need. And that all equals dollars.

 The equipment, itself, for ABR and OAE is expensive. It's an expensive program to launch and an expensive program to maintain. The equipment needs to be replaced. We were told, every five to seven years. The equipment, with each child, we have to use what we'd call consumables. So... probe ear tips, electrodes, those things cannot be reused. They have to be thrown away and the items are proprietary. You have to buy certain ones that are compatible with the system that you have.

 So... again, that's just another cost involved. And we have noticed an impact to our campus services, we have the same jobs before our ABR centers that we have now. So... we had to bottom better time‑managers. We had to tell people, that'll have to wait until the afternoon or the next day. Maybe we miss a meeting because our baby appointment runs over. So... we're still doing our jobs and we've been doing it well, it's been challenging as far as time. And... again, that skillset, we continue to feel, you know, we're continuing to get training. We're continuing to reach out to people about their protocols and making sure we have the best practice that we can give, so... we still feel like we're still building our skills and at the same time, when Michelle and I decide to move to an island and open a Tiki bar and leave this audiology gig, the school is going to have to find an audiologist that has that specific skillset to work with babies for threshold searching.

 So... we wanted to put it out there. Does your state School for the Deaf, how do you use them as a resource? Would this model be possible in your state? And we'd love to talk to you about it and... I mean, I had to put the flag in there. It's like the best flag from the 50 states. So... this is our contact information and... you can reach out to us any time. We really glazed over the grant part of things, but we're happy to share with you how the grant was written and... things like that to help you push us forward, where you may be from, and... we wanted to give a shout out ‑‑ this is Dave. The guy we keep talking about. He's the audiologist that works on both campuses. He's completed the ABRs and our EHDI coordinator, Tanya Green for her feedback and everybody at our school that supported us in developing this. We're just happy to be here and we're ready for your questions if you have any. Did you know Black Eyed Susans are our state flower? Aren't they beautiful? I put one of those on here too. Ocean city, that's right. There are so many things. I had to pick and choose, right? About Maryland, it was tough. Have you experienced this in the state you live in? Anyone going to happy hour after this? We're ready... okay... yes, we got one.

 All right... thank you ‑‑ oh, yes, our slides are uploaded online. So... if you miss anything... you can refer back to it, they should be on the EHDI website. Okay? Not the Maryland pictures ‑‑ I took those out. I figured ‑‑ I didn't want you to waste ink and resources and things. All right... thank you so much.
[applause]

 [Presentation concluded at 5:28 p.m. ET/3:28 p.m. MT].

 "This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings."