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EHDI

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Oh the Places You’ll Go! From Parent to Professional

2:15p-2:40p

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>> Can you hear me in the back? Okay...

>> Hi, guys, I'm Emily. I'm the room monitor. I put evaluations in the middle of the table if you'd be willing to fill those out. At the end, I'll be in the back. You can hand those to me before you leave. This session is titled Oh the Places You'll Go! From Parent to Professional.

>> I'm Andrea, I'm a registered nurse. Also a teacher and most‑recently a teacher of the blind and visually impaired. I'll be going over how I got from A to Z. I love this, Oh the Places You'll Go. I taught high school for five years. The quotes in this book. When you graduate from high school, you can have the world open, it's your oyster. Become a parent, have a mortgage and things settle down. Because of my life circumstances, I really use them as a springboard to help others. I'll tell you that story and hope that if anyone is out there who is a parent or any patients out here... okay... might be inspired to do something similar to make the world a better place for our kids who are deaf and hard of hearing.

So... the long and winding road. That's me on the left getting my pinning from nursing school. My favorite aunt who also was a nurse. She worked with adults who are disabled and marginalized and a big inspiration in her own life towards me, for me.

When I was in college, I think I switched my major monthly. I have wildlife biology credits, random. Finally decided to go into nursing. I was Pediatric and NICU nurse for awhile. Saw some pretty tough cases. Kids who passed away, kids with cancer, kids with random genetic diseases. When my husband and I decided to have kids, he's an engineer, he's super logical. That's all you see, you're kind of a little biassed. I'm like, that's true.

Here's me on the right. This was a rare condition called crab A [phonetic] disease. Born totally healthy, but then degeneration of vision, muscle weakness, wears glasses, will probably get a trach at some time and has a G tube. Sweet little guy, doesn't speak, but I read him a book and he's enjoying it. You can see his smile there. He's laughing and we're communicating away.

Okay... so... I have three kids. This is my first son. Wyatt. My husband is from Montana. We're not Cowboys, but my dad's name was heard. Wyatt Herb. My dad's name was Herb. He passed his hearing screens, not worried about anything. Fast‑forward to my second son, born close to ten pounds. We weren't too concerned at birth, I thought he was so big he had fluid in his ears. There's his referral. He startled at noises and dog barking. An excellent referral form. They're doing work in their state, the nurse sat down on my bed, told me how important it was to go on to follow‑up, wrote down the appointment for me. I had another kid.

So... I went in, by myself, like a lot of you moms and he was diagnosed with a hearing loss. Moderate/severe, bilateral sensorineural hearing loss. They recommended hearing aids, and our state still doesn't cover hearing aids. Pretty devastated at that time of my life, to be honest. So much so that my husband got me like ten self‑help books. When Bad Things Happen to Good People.

He got hearing aids on March 11th. Super smiley when he heard my voice for the first time. That was fun. Didn't know anybody that was deaf or hard of hearing, no exposure, like a lot of you guys. What helped me. We started working with a speech therapist and her son was born deaf. He went into speech therapy. That was an ah hah changing moment. She walked in my shoes.

Okay... obsessed by what caused this. I needed to understand why I was so obsessed. To me, it was like a disease, because at the hospital, we'd get kids in, maybe they had neck stiffness, they had high temperature, we were like "it could be meningitis." We do tests to figure out what is the cause. That's my nursing background. I had him tested for CMT, toxic osmosis, you name it. Did a CT scan, had his eyes checked out, nine months of age, everything looked fine. We couldn't figure out why he had the hearing loss. I think it was for my guilt, I thought I did something, as a mom. I think some of you moms can relate to that.

So... really weren't sure what caused it, but... there's Ryder. This was taken about seven years ago. We wanted one more kid, and wanted a girl. We tried and we got Kylie. She was born on term, no complications. She referred on her hearing screen and was diagnosed with a hearing loss. I was like, second rodeo, I got this, I understand, I know the toddler program, I know speech therapy, how to keep hearing aids in, and I was super excited I had a girl. Now Ryder won't be a loner in the family. I knew it was genetic, huge weight off my shoulder. Out of my control, I'm okay with that.

This is her at seven weeks with her hearing aids, and... still obsessed. A friend of mine had three kids who were deaf and hard of hearing told me about this study in Iowa talking about the four genes that cause hearing loss. Kylie was 10 weeks old. My family sent their blood to this genetics team in Iowa. I kept e‑mailing the researchers "do you have a result yet?" I took a Gallaudet class in genetics and was worried about a couple of those that were deaf plus. They're like "we'll let you know when we have the results."

So... I went to a genetics doctor and took Ryder in when he was about 5. I heard about Usher Syndrome, which is vision loss as well.

On my birthday six years ago, my pediatrician told me he had the news, the genetics results back. I was taking my kids to swim lessons. He told me my kids have Usher's Syndrome. I was completely devastated. To receive that news on the phone, to me, is like getting a [indiscernible] for pancreatic cancer. Through your will together. It seemed like the end of the world to me. I called my mom, my husband, my best friend and I was sobbing. That was taken around that time. My kids were like... what's wrong? My older son, Ryder, these two said they'd make me so happy. They didn't know what was going on.

When my first son was diagnosed with hearing loss, I took every life preserver out there. I don't know who this person is that wants to come to my house, but yes, please. I don't know anything. I'm the one that asks for directions.

I called the Iowa School for the Deaf and Blind, probably that week. Some wonderful ladies came to my house. I cried with them. I said "are there any sort of classes I can learn as a parent?" Now I'm faced with hearing loss and also with this impending vision loss. These wonderful women came and told me about ‑‑ I was asking if there's anything local, nationally, they pointed me in the direction of Texas Tech University. There's a program that has for teachers of the blind and vision impaired. They got my e‑mail and said there's like scholarship opportunities, you had to be a teacher to apply, which I was. They'd send me any information they had available. If you can see that, I'm getting old now. I have to get close.

It says would you tell me, please, which way to go from here? He says it depends a good deal on where you want to get to. I love that because... I could have stayed in that anger space for a long time and not used my resources as a human to help others or just be snuck that spot of anger for a long time, but... through fortuitous circumstances, able to roll in a different direction.

A quote from Helen Keller. She says "I believe there are angels among us, sent down to us from somewhere up above, they come to you and me in our darkest hours to show us how to live, to teach us how to give and guide us with the light of love." I feel like those women that came and opened this door for me were those folks.

So... I applied to graduate school. I had to get a couple hoops, you know... it wasn't super easy, I had to do a lot of work to get there. My husband is really easy going, I'm like "I'm going to do graduate school" and he's like "okay." I entered Texas Tech in Lubbock. I was in Idaho. It was grant funded by Office of Special Education. It was a two‑year program. Online. We had visits to Lubbock and Austin completely covered. Travel, books, tuition, everything. There were two classes ‑‑ I got my teacher of the blind and visually impaired certificate to teach through this program and I spent like six credits of my own money to finish my masters up, but a lot of those classes overlapped if that makes sense.

That last year, when I was still in school, one of the teachers of the blind moved to Oregon. I shadowed her for a day. They had emergency certificates because there's a shortage of teachers. Audiology, there's a shortage. SLPs, there's a shortage. In this area that a lot of us have walked into through our children, there's a huge shortage that you may or may not be aware of.

I was offered a job, I'm going on my fourth year, I worked as a teacher of the blind and visually impaired for kids who are zero to three years of age. And I love it. In some ways I'm nursing. They're happy when I come, they're not screaming. That was the case when I was a nurse.

I've met incredible folks along the way. This man is from Texas, this man is from Haiti. He had cancer of the retina. Had both eyes nucleated. Lost his hearing. He wears hearing aids. I think he had partial hearing loss from the chemotherapy. He runs around the campus with his guide dog and finishing his undergrad at Texas Tech. Amazing people I'd never have the opportunity to meet. People here, people through this had it not been through what my kids ‑‑ like that door in Alice in Wonderland. That pull through.

I'll have my PowerPoint on the EHDI website. There's quite a few resources. These are just some examples of things I've done. On the left, working with kids. I work with zero to three, but help with older kids as well sometimes. They're playing a game with their canes and the go ball. I work with about nine Early Intervention Specialist teams. If you're familiar with early intervention teams, I work with two regions. I have about 30 kids on my caseload and I have to go to meetings to keep up monthly. The physical therapists might talk to us about motor issues. It's really fun. I get to work with all those disciplines. Speech therapy, OT, PT, developmental specialists, the parents and kids. It's a fun combination.

These are all the programs for Deaf Ed. And I'd just like to interject. These are other kiddos I work with. On the left, was a girl I just worked with. She has a genetic disorder. They're not sure what it is yet, but she's globally delayed. Her mom is developmentally delayed. I love working with these parents. To get in the home where they live. You have a ‑‑ I developed a deeper appreciation than when I was a nurse and probably, to be honest, was judgmental. I'm like "why aren't you doing this?" And "why aren't you doing this?" Now when I go into the homes, I understand more. I have this level of empathy that I'm glad I've been able to cultivate.

The guy on the right, we had play groups with deaf and hard of hearing, but there weren't any for blind and visually impaired kiddos. I started offering those in the summertime. That's one of the little guys I worked with, he was a triplet and lost, the mom lost one of the triplets. He developed retinopathy in prematurity and is completely blind. Just hanging out, bouncing on the ball and fun to work with these kids. I love it.

I get to work with teenagers too. When I taught in high school, I dissected a lot of stuff. Hearts and eyeballs. We work with kids who are teenagers, blind and visually impaired at our condition for the blind. I was like "have they ever dissected an eyeball?" We had a class where we dissected eyeballs so they could learn about their own eye condition. We want our kids to be self‑advocates for hearing. I have a moderate hearing loss, I can hear you better if I'm this far away. We give them advocacy and we made fake eyeballs. (?) That was a fun thing.

So... how to do this if anyone's like "sign me up." Does anyone here have a teaching degree already? You do? Okay... if you have a teaching degree already, you're set. You can really apply for like blind VI, deaf and hard of hearing because they like those endorsements. There's a lot of different programs, teach for America, you can type those in all the websites will come up with all the information. I won't go into all the [indiscernible], specific for New York City. Mississippi, oh my word, they have like, you can get a signing bonus. Lots of cool things. I was researching this, the scholarships. Mine just fell in my lap by inquiring, the more research, I'm like, holy cow, teachers are a shortage. Especially special ed. Deaf and hard of hearing, blind, VI, all of those under that special ed umbrella. You can have forbearance on your loans, you pay back mine, I'm sure I have to work every two years for the grant I got. I guess if you're like "I hate this," that'd be a nightmare, but you probably know before you go in.

I'll probably do this until I retire.

The National Association for Alternative Certification has information as well. If you go to your state Board of Education, every state has an alternate teacher certification. So... for those who have a bachelors in HR or mathematics or English... there's some great resources out there. They want people with real world experience to go in to do these great programs online. Without spending a ton of money on school. It's ABC teach. It's like $1900 and you can have like a math degree and get your teaching certificate. That's pretty cheap for college, anymore. And get your teaching certificate and you can go on and do audiology or apply to speech therapy programs. There's tons of grants for all that stuff. Kind of cool.

These are tools of the trade I use. I brought some of my little ‑‑ I love stuff like this. My car I drive around with in the state. I look like a clown. I have pinwheels and I drove this minivan around for awhile. Someone's like... whose car is in the driveway? It's mine. I have all these fun things I use. On the left is an object calendar. For kids who are nonverbal. It's scary. If you're blind or visually impaired, things are always done for you. You can't act on the world yourself as much. Now it's nap time, I'm going to give you your G tube feed ‑‑ these are a lot of tactile symbols. This little kiddo gets oxygen therapy, AFOs, morphotics and the bunny is bed time.

Kind of fun toys. Teaching concepts for kids who are blind and visually impaired. Think about everything we learn and those kids who were born with normal hearing or they just ‑‑ they overhear things. Same thing with the visually impaired. Concept like large, small, rough, smooth... tactile symbols. This just shows you a couple of the things that I use.

Has everyone heard of the expanded core curriculum for deaf and hard of hearing? No? Okay...

Look at these. Sorry for all the websites. I didn't have enough room. Expanded core curriculum is what defines the concepts we use as teachers of the blind and visually impaired and specialized instruction for kids. There's actually an ECC for students who are deaf and hard of hearing. So... I urge you, as parents and providers to go to that. It has amazing stuff of what we want our kids to know. It includes things like audiology, career communication, family education, functional skills for education success, self‑determination and advocacy. Social, emotional skills and technology. Raising two kids who are hard of hearing, these are huge things, so... social emotional skills, all of that. So... I love ow both of these kind of vocations parallel each other.

Okay... let's talk about funding. Like I said earlier, lots of student aid, forbearance, forgiveness, a lot of teacher grants out there. All of these websites have all that information on it. There's actually something called the public service loan forgiveness program. It's under the teacher loan forgiveness program. There's lots of ways to tackle this. Teachers don't make a ton of money. If you're from Texas, Texas has a reach across Texas program. A competitive program that you can apply for and receive a grant, a scholarship award. There's a ton out there to start researching. This is more information on Deaf Ed and covering Deaf Education to be a teacher of the deaf.

Okay... let's see here... what other things can you think about that you worked with that you could ‑‑ these are just more student aid. All of these are ‑‑ I read through all of them, researched them. They're great, great sources of information to look for if you're looking for ways to fund this. Call up your ‑‑ the biggest thing is go to your School for the Deaf, school for the blind and visually impaired. Talk to the director for outreach. They're going to be the person in your state who may know like, grant opportunities, like the project Sasi [phonetic] that I did. There's deaf and hard of hearing, teacher of the deaf, ASL interpreting. There's scholarships that you go to ASLhonorsociety.org. Service coordinators, how much parents would be amazing at that. To know, we know, we've been there. SLPs, if you go to ASHA.org and type in Financial Aid, they have a ton of information there. Developmental specialists, Early Childhood Education, audiologists, that's a dire need as well. We don't have any in the northern part of our state. Deaf‑blind intervener. There's tons around this field of our kids who brought us here. So... one thing I think about parents and I know our speech therapists I went to. Her son is deaf. Another lady in Idaho, she became an SLP. When you have that, you're like... I'm on this road too. I feel like you have this huge field of experience and connection with parents. When you, when you have ‑‑ you're like "I did early intervention" you did buy‑in. It's easier to get into homes and earn the respect of parents. You're legitimate and you can empathize. Empathy is a big thing. When I was a Pediatric nurse, I had dogs. I felt I had empathy, but not as much as I know the pain now, when you have your own kids and something you weren't expecting or wasn't on your radar, happens to them. Humans are so resilient, you recover. Here's links for where the schools listed all for the blind and the deaf which we have in your state. I think Wyoming might be one that doesn't. This little guy I worked with, he was born completely blind. For kids who are blind, for those who have kids, they love looking at their hands. If you're blind or visually impaired, you don't have that visual motivator. He learned to clap his hands, so exciting. Think about what you use your hands for, to twist, play with toys, manipulate things. This was a big deal.

These parents sent me these videos, they're like "look at what my kiddo's doing." They love it. This little guy on the left is a kiddo with occular cutaneous albinism. Very light skin. Light eyes. We're working on a puzzle together. There's the little guy on the right. We did a craft that day. Sometimes mom was so stressed out. You could feel her anxiety was through the roof. So... it was Valentine's Day, we did a craft and had a fun time. You have to play with these kids, where they're at. As a nurse, I was able to give meds to the kids. On the left, there's a guy, the neatest guy, born completely blind and... plays a piano, super fun to talk to. We had a great time, we went snow‑shoeing, skiing, had a wonderful experience. You know him? I'm like... is that your son?! Isn't he awesome. He's so fun. Yeah... so enjoy talking with him. This is a picture of my daughter and I on the right. Knowing that they're going to have vision loss at some point in their life, I'm able to share all these experiences I have, which is huge for me and huge for them.

So... we're looking at Tea Time Mountains [phonetic]. The You Shall See Wonders, things I put on her greeting cards and birth cards when she was born. I love this. As part of this book, it says you're off to great places, today is your day, your mountain is waiting so get on your way. I really feel that as broken as I was when I received that diagnosis, probably one of the lowest parts of my life, and my dad dead when I was in pre‑school. (?) I've had some tough experiences, this is one of the hardest. So... I felt broken a couple times, but I felt like by giving pieces of yourself away by helping others, you feel whole. If you have any questions, please let me know. That was a lot of information. I hope I didn't exhaust their hands. But these are some of the things, real quickly, the toys we use, teaching concepts. These apply to deaf and hard of hearing. These are things I use. Smooth or what not. The signing times, these are kind of fun. This is in braille and has the sign with it as well. It has tactile things, like lizard. I have a lot for my kids, trying to teach concepts, we work on that, we play, we do peek‑a‑boo and sometimes it's very, if you really like to be creative, some kids just trying to work on their picture graphs, I got this like container and have to use this to get that motion out to get a goldfish cracker out or something of that nature, this is a slate and stylus, I get to use all these things with my kids. We playback and forth. Some of the kids I have, have cortical visual impairment. Their eyes look great, but their brain isn't interpreting. They can see yellow and red. One of their outcomes might be focus on mom's face for five seconds. They're really drawn to the color red. A lot of fun, inventive stuff that I get to do in my daily job. I love it. Any questions? Okay! Thanks, you guys. If you have any, let me know. You're welcome.  
[applause]

[Presentation concluded at 4:42 p.m. ET/2:42 p.m. MT].

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