3:00pm ‑ 3:30 pm MT Capitol 3, Block 7

Why Deaf Culture? ‑ Considerations Shared by a Hearing Mom of a Deaf Child

>> Been to Colorado before. Two years ag I got to go to Estes Park. Loved it. My husband hunts here so not been here together yet though. Excellent. It's working.

Okay.

So thanks for coming. And I am not going to poll who's in the audience because I feel like I have a lot of stuff to go through. And I would like people to feel comfortable here and not feel like you're saying your one thing or another and not talk about labels. Or label yourself.

So I hope that I'll be able to expand your perspective as well as your expanding mine. So I encourage you to connect with me after either through email or ‑‑ you know anyway to connect because l like to hear what people think.

So we have to go through objectives quick. You guys probably know what these are because you chose to come to this session.

So

I had met my husband in white water at school which is one of the university systems in Wisconsin.

We have a very strong sense of community in Wisconsin.

Had my daughter Grace and 23 months later I had my daughter text.

We did not know that she was going to have downs so it was quite the surprise when we were at the hospital. So that normalcy I expected was not given to me.

But it wasn't unfamiliar me working with special needs groups. I had a cousin Lori who was a same year as me who it cerebral palsy at birth. So the idea of raising a daughter with down's was something that I accepted. I think somewhat readily.

But it was still pretty difficult because it wasn't what I expected. I also worked with special needs kids in a healthcare camp in Michigan for a few years and so saw the variety of needs that kids can have. Worked in federal prison with inmates. Worked with elderly and emotionally disturbed teens so kind of I've always been the one that has rooted for the underdog and so I embrace their daughter. We embraced our daughter.

But it took us a few months to get the news about her hearing.

And once we heard, that she could not hear, at all, I think that took me a little longer to accept.

You know it meant that I was going to have to raise her a little differently.

So when it took many months I asked the audiologist what can you give me to prepare myself to prepare for this whether she's going to be hard of hearing or deaf. They were like we're really uncomfortable to give you a definition about deaf adults because it might not be that. Maybe she's just hard of hearing so let's just wait. That was back in the day the Internet 1998 the Internet was terrible. So I just said Okay. We'll just wait. Nine months of age, she had frequent ear infections due to Down's Syndrome. She was sedated. We did the sedated exam in the hospital and that's when we heard the news she was deaf. So deciding what to do now. We had a any baby with many needs. We met with ‑‑ that's the list of medical professionals we met within the first ‑‑ actually all of them within the first probably month of her birth. And then the audiologist started to become as we were in the birth to 3 program and we had a speech therapist on the team who was saying you need to get her in for some hearing exams. Because we small rural hospital did not have newborn hearing screening at the time.

So again, deciding what do we do now?

>> We met with the birth to 3 providers after the geneticist said here's a graph. Here's how kids do without early intervention that have Down's Syndrome. And here's how kids do without early intervention. So we were like Okay.

Let's go for it.

But it was still a lot to learn. Terminology we had to learn. Completing needs assessments. Being asked what are your goals for her? This baby of one‑month‑old. I don't know.

You know? That's a big open questions for families at that time. Develop an IFSP, never Having seen one before. We had to discuss the cost of our plan and figure out whether we should go the cheaper route with birth to 3 or go through insurance and deal with all of that. We had to sign her up for insurance. The silver lining of her having down's is that all of her service has been paid for through Medicaid. Never had to deal with the cost of hearing aids, any of those kind of things. We had to schedule therapists in our home so this is before primary coaching so we had to get used to a different person. There were five of them. Five different people in our home. Every day we had someone who was a provider in our home which for me was really difficult being a pretty private person. And it was also pretty difficult for my daughter's older sister who felt like why is Tess getting all the attention. She felt upped. It was a tough road but one of my questions after we found out the news of her hearing was, you know, who's going to be her community? I'm a sociologist so I research and read biographies and you know, anything I can get my hands on. I know learning from others is where I get my information. So how is she going to communicate? Who will she communicate with? I read everything I could get my hands on and I concluded that we needed to learn sign language and its culture.

This quote is from ‑‑ I was on an elder meditation daily kind of affirmation email and this came up when Tess was probably 4.

And it has stuck in my head.

So in you don't know the language, you'll only see the fur surface of our culture. The language is the heart of our culture and you cannot separate it. The more I learn about the deaf community just feel like this really is meaningful to these discussions about deaf community.

And my daughter. But where the deaf adults? Where were we going to learn sign language. We lived in a small community of 2,000 people. An hour from any big city, Madison being the closest one. Who were we going to practice with. How could I get my extended family to learn sign language. This is before face time, Skype. It was all phone we were still doing round robins with my family through letters through the mail, you know? How can I convince us that we all needed to as deaf and learn her native language while still using hearing devices which we wanted to give her a chance to hear.

So whoops. I love it.

If you're interested at all in one of the first books I reed which I tried to have my family read, some of them said it was pretty difficult to read because it kind of goes back and forth with this person ‑‑ there's five different people's story in the book. It's called train go sorry. And I see a lot of heads nodding. It was a very powerful book for me. Having read it within the first year of Tess's diagnosis.

It explained to me how deaf adults feel about their world and the hearing world and deaf world. So I just wanted to throw that out there. It's a really good book to read. And later on I read "far from the tree" which is another really good book which talks about different special needs groups and deafness is a chapter, which is a very powerful chapter as well.

So one thing that ‑‑ another thing I concluded I should say, is that deafness seems to be the only condition where there's a cultural component to a parent's decision of what to do next.

Along with a medical and audiology discussions that take place with families. We could all benefit from a discussion about deaf culture when parents are told the news of their child's hearing level. There is a man, deaf man named Ken Glickman. He has this term called deafology if anyone's interested. And basically, what he says is in order to understand where we are now, we need to value a connection to history and the keeping of traditions.

Stories of the past are treasured but they also serve as a mechanism to teach about the future and the present. This isn't unique to deaf culture, they're shared with minority groups their history is very important to understand where we are and where we're going. So I'm going to do a very brief history. Of deaf culture so maybe people who aren't familiar with deaf culture to understand where the deaf community is coming when they say we need to support these kids now as they grow up. And maybe this is why.

Back in the day of Aristotle which was around 384B.C. That's where the term deaf and dumb was kind of developed, not developed but was used.

People thought that people who couldn't speak also couldn't think. So that's where deaf folks were back in the day. Then around 1600s was American Sign Language was developed and used.

And what I've read it seems like it was Martha's Vineyard was around this a nice community where there was a larger community of folks with hearing. Hearing community learned sign language along with the deaf. It was a natural thing to use sign language to communicate.

And then in 1880, there was something called the second international Congress on education of the deaf in Milan. And that's when they declared that oral education was superior to manual or sign education.

And it was banned in educating deaf kids. That's a big change from people feeling they were accepted to then no.

I was going to talk about it briefly later but we had a deaf mentor. We were fortunate to have a deaf mentor in Wisconsin. We were 1 of the first families. When is the program going to start? But she was the one that told me some stories and I met some of her deaf friends about hands being slapped in the classroom. The whole focus on the lips and speaking and not any attention to really how some deaf kids learn through visual language and not through hearing and speech. So kids taught other kids how to use sign in the schools and sometimes had to hide their use of sign language in the schools.

Eventually the civil right movement came around in the 1960s and we all maybe know the history of the other minority groups. In America and how they protested and spoke up for their need to be human right for different things.

So the deaf community also had some developments in terms of feeling like they're rights were being addressed. So NAD started, are, TTYs were developed. Closed captioning, sorry, the interpreter, just can read the rest of what happened around that time. And then finally, the 21st Congress of education of the deaf rejected at second Congress resolution. So that was a big success.

So now where are we? We are today there's ASL classes in the community, there's baby sign classes, there's people working at hotels learning sign language so they can communicate with their customers.

We're seeing commercials where sign language seems like it's valued and accepted. So we all know about Neil DeMarco probably. Dancing with the Stars and America's Top Model and so today we have all of the strength and positive view point of sign language.

But, if you're going to go a certain route signing you shouldn't sign with your kid. I'll going to acknowledge that this ‑‑ I don't know if you call it cartoon, graphic, whatever you want to call it can be pretty offensive to some people. When I first saw it I was at AG Bell conference at the same time they had the deaf bilingual coalition meeting in Millie that was 2004, 5. I tried to jump to both conferences and there was protests outside and deaf people if you can see it. It's a hearing baby who is happy and signing and the deaf baby's hands are handcuffed and sad about that. This is the current state of what's happening.

The issue of identity was talked about in some of the sessions today and trying to see if Anita was here. But it was very powerful. I listened to her presentation about deaf identity and if anyone has a chance to look over that PowerPoint, I think it's very informative. How can we avoid deaf identity crisis which occurs whether we shield ourselves and our children from learning about deaf culture and meeting deaf adults. I did a presentation a couple years ag at EHDI that was about Thomas Holcomb and this how he adopted Epstein's model of theory and seven categories of identity. I did it with two other moms. Actually, one mom and another one that Nancy Sager from California. I'm not going to go into depth here because it's a lot of information but it's stories of deaf adults who shared that they didn't know ‑‑ that there were other people like them. And how when they became an adult and met other deaf adults, this identity crisis happened. They were raised either/orally or maybe were sent to ‑‑ I'm jumping ahead here. Another story that stuck with me was a deaf adult who never met another deaf person growing up.

And they thought that they were maybe going to die as a kid because they had never meta deaf adult. So again, it's a powerful story and I'm not saying it to ‑‑ you know, really surprise you but it's just so important to have kids that can't hear like the other kids in their classes to know that they're not the only ones like this. And know that there are other deaf kids like them and that there's deaf adults.

The other identity crisis that can happen with families and I've heard stories, read stories of you know, they do meet other individuals as they're older and they wonder why their family didn't acknowledge their child's deafness or that there's deaf culture. And that they might then turn away from their family or question whether the family really accepted this person as they really were. And either feel like their family is ashamed of them and why didn't you introduce them by the people, I keep encouraging that the earlier you can learn about deaf culture and what it means to be deaf and not just the sign language but all the other things that go with it, is the reason it's better ‑‑ so how can you ‑‑ learn did deaf culture and sign language. We jump in and get wet and uncomfortable and cold.

But you can have fun. And you meet necessity people. And you learn of new praises where you can go swimming. You know, there's lots of different things and the other ‑‑ I guess the other thing I can say is because Tess had her Down's Syndrome, we know that there were ‑‑ was a potential that she wouldn't be able to speak. Because kids with down's have slow motor skills. So it was another push for us to learn sign language. We were fortunate to have friends that had a boy with down's syndrome that was a couple years older than me and Tess. And I see him now he has a difficult time communicating what his wants and needs are. He had a mild hearing loss, his parents didn't learn sign, didn't push the use of hearing aids. And I'm ‑‑ I'm copy with the route we've taken with Tess because she's ‑‑ I think she's in a better place.

So the other thing about jumping in is you're going to feel some of these feelings.

I thought this was a pretty good graphic for me.

Any time I'm a pretty shy person.

And any time I felt like I was learning a new sign and having to use it in public, or role model with other people in the classes, you know, my heart pounded out of my chest, my fingers shook, sweated, you get a headache because all of this information. I mean, it's a lot to retain.

You might feel the same way but you need to figure out a way through that and get comfortable. It's definitely a new language. I know some of my in‑laws tried to take sign language classes and they were like my brain is too old to learn that new language. And in the early days my extended family took sign language classes but they didn't continue with it. So it's ‑‑ I guess I'm acknowledging that even though yourself and maybe you're immediate family is going to embrace the idea of learning sign, you might experience the roadblocks of other family members saying yeah, she had an implant. Or why don't you get her an implant or you know, all of those kind of things that you might hear from folks about why sign language isn't anything you should worry about. She did have hearing aids no, benefit. Implant at age 5, used it, didn't see a lot of benefit and two years ago she had health issues and chose to take it off. She didn't like it. We gave her the opportunities to learn language, auditory and visual. Learning new language takes time.

It takes opening your civil up. It takes not being judgmental about yourself. Or others.

It takes not caring what others think because you are going to draw attention to yourself and people at McDonald's are going to be staring at you because you're using your hands and so you just have to try to ignore other people.

Some people are scared away from learning because when you interact with a deaf individual, it can be too much at once.

And

You think I'll never be able to sign like that so I'm not going to start. But you just need one of the first signs I learned was probably slow. So you meet a deaf individual and they see you can sign and they start signing at you. Slow down.

So it's an important sign to know if you're going to be learning sign.

And initially things may feel awkward but I did come to realize that it is natural in the gestures that you use, facial expressions, those first few classes that we took or videos that we watched, you know, they focus so much on your facial expressions, need to match with the sign and there was too much focus on that because really when you start signing, it kind of all comes together. And we needed a lot of exposure.

Being like I said in a small community how do we get that exposure? This is her at 9. She is now almost 20.

She was pretty happy at this time. We had attended a parent support group called shore to shore. It was a literacy based support group. We did that from the time we found out she was deaf and we had a deaf mentor. She went to a school in Madison with other direct peers and we decided to bring her back to our home distracts because kids in the community wanted to know who she was and also before iPads and she was up locking the back of the doors and the car on the highway and it was like this is too up safe and the deaf and hard of hearing program was starting to fizzle. So we did ‑‑ I mean, I did everything I could to learn sign language. We went to family learning vacations that a center in Wisconsin supported. I went to two symposium on deafness. I was fortunate to get hired by the EHDI program. We used TTYs and we now have a video phone. And ‑‑ yeah.

It's a lot of work but we had to do it. There was no really alternative. One thing I want I wanted to leave you with today was with families and each other in terms of that you're working with, if you could switch to strength‑based vocabulary versus possibly a negative impact or negative solution. So I'll just have you read that.

It takes getting used to our EHDI team instead of saying "hearing loss" because we heard from the deaf community that hearing loss is congenital is not a hearing loss. So we've been learning to say deaf and hard of hearing.

But I know there's people have different opinions about that as well. But in the other disability arenas, you know, they've been talking a lot about instead of saying disability to say differently‑abled.

Oar you're putting judgment on that person's condition. They're just differently‑abled. I've also read and watched a lot of things about people with autism.

And even though they're not verbal, how they learn to communicate. We've learned about augmentive communication devices from my daughter and visual schedules and all that to support those other needs that she has. I like to say opportunities instead of options because options seem like you're having to pick. So where are we today? This is her, pretty happy, she loves circuses, we were watching a circuit outside. And she graduated from her local public high school last year.

And the picture on where she's just the three in the family, my husband and my other daughter Grace is her first day at Wisconsin School for the Deaf. And when we asked her in the past if she wanted to go to that school, no no no no no. She loved going to the plays. She did not want to stay there. Once we said hey, how about college? College? She knew her sister went to college and would come home on weekends and she was all for it. So that was right before we were ready to leave. It's been a struggle with her having to be independent in the dorm and us having advocate that she's deaf, she needs to be here, she's needs peers because again she was not the only deaf kid in our school district but the other deaf child had gone to the School for the Deaf.

So that's my family, that's my story. I invite you to connect with me. I really do want to hear what people have to say. I also work with some of the birth to 3 counties in Wisconsin and we're educating providers all the time and families about what's the best way to have a healthy identity of your child but also of yourself as a family.

And how do you get over those feelings and hurdles and very honored to be here with you. Thank you.

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