>> Well, hello, everyone, I'm Brenda and I'm the room moderator today. I'm going to take this off for a second.

And thank you for coming to our "Creating Meaning Together: Understanding EI from a Social Model" session.

As you can see, we have the tables set up to -- we're going to have a lot of interaction today. And one other thing I try to remember is at the end of the session if you could please go to the cVent event app if you haven't downloaded that and do the survey at the end of the session, we really appreciate your feedback on that.

Yeah, so I will be here if you have any questions or if there's any concerns with anything. But now, I'm going to officially introduce your speaker today, Betty and I will let her introduce herself as to what -- what her role is. And I'll be passing the mic around for you to speak into it. So that we can capture the CART, as well. And Betty will be signing for herself. And the interpreters will be voicing for her. Thank you.

>> Okay. I want to start by saying thank you. You're very brave for joining a three-hour session this afternoon.

I plan to provide one or two breaks throughout the session because three hours is a long session, let's be honest, I'm going to need a bio break myself.

Also, I am thrilled to be discussing this topic with you guys today. Understanding that this is my dissertation topic. So it is my heart. And it has been for many years. So thank you for joining me in this discussion. I would like to start with introductions, if that's okay.

I just want to know who you are and where you're from.

What your role is.

Maybe what you would like to take away from this session or what you would like to learn from this session. And I forgot to add my pronouns. Sorry about that.

My preferred pronouns are she/her/hers. Would you mind starting on the right side of the room and then we'll go around? .

>> Okay I'm Alisa Weeks I'm from Knoxville, Tennessee. I work at the Tennessee School for the Deaf in the birth to 5 language to literacy program I'm also a Parent Advisor with the SKI-HI Deaf Mentor Parent Advisor program I'm just really excited to be here I really want to get a better feel of how we can establish the different opportunities for families together at this young age when we're working with them.

Did I get everything?

>> You did.

>> Hi my name is Julie Beeler I'm also from the great state of Tennessee. I work at the University of Tennessee. I'm an audiologist and a speech pathologist. I wear a couple of different hats in the program. My current title is I'm a program liaison so I do outreach and promotions for the department. But I also co-teach an early intervention class. With a colleague of mine. On a grant that we're currently on the last year of the cycle. Will be upcoming. That partners Deaf ed students with SLP students to kind of let them look at each others program and learn from one another and actually Alisa and I team together because she oversees an experience that some of the grant students have. With her program that she just described. So it's a beautiful arrangement. So we're excited to be here.

>> Hello, my name is Carrie spainggler and I'm on educational audiologist here in Ohio. I had a short drive.

And in addition, I also grew up Deaf or hard of hearing. So I have a cochlear implant and a hearing aid. And everyone in my family is hearing. So I'm just here to learn more.

>> Hi, everyone, my name is Lauren Burk. I'm from Wisconsin.

I am a speech-language pathologist and part of our state's EHDI program providing intervention.

We have an intervention team who is providing supports for our Birth to 3 Program. Statewide.

So that looks like I'm providing coaching and support to other SLPs throughout the state. To increase their knowledge and capacity for supporting little ones who are Deaf and hard of hearing. My emphasis is supporting families who have chosen a Listening and Spoken Language route and I have a counterpart who is a Deaf professional who supports families who are wanting to focus more on visual learning, visual communication and ASL.

Happy to be here.

>> Hi, I'm Darcy Beaver. And I just put a lot of faith in the airline system and I literally just landed.

It was a little later than I was supposed to be.

So I am from Kansas. I work at the Kansas School for the Deaf. And I'm an early interventionist in a program that's called sound start.

So I travel the state of Kansas . Doing -- serving families birth to 3. Working in conjunction with the local infant toddler agency.

We also do a language assessment program. Where then we look at the receptive and expressive language skills in English and ASL.

>> Hi, everyone, my name is Stacy Abrams I'm the Project Manager for early intervention in the national program and outreach at the Clerc Center.

And I am one person of a three-part team here today.

And we are a part of our EAL. The regional early acquisition of language program. .

We focus on birth to 3.

And supporting different interventions within the Deaf Ed system as well as supporting family and focusing on early acquisition of language to make sure no Deaf and hard-of-hearing children are left behind. And I am here to learn everything you can teach us today.

>> My name is shen nay Rouse and I am an -- I'm an early Project Manager working with Stacey. Everything she just said I ditto and I'm really happy to be here and learn more about you, Betty.

>> My name is Debbie Trabani. I'm the Director of the national program and outreach center for early intervention . I'm also responsible for our EAL.

And I work closely with my colleagues here. And our program is really to identify different possibilities in our programs and projects. And provide funding to support those programs. That include families, early acquisition of language for the family.

And we work with people in Tennessee. We work with several southern states for now.

And we're still working on expanding our network to include different regions of the United States. So we'll be working with other people, as well.

So we're going to be working with people from all over the country to work on service provision, early language acquisition, support to families. Really you name it, we do it. And reach out to us if you would like some more information.

And tomorrow we're hosting our luncheon for those of you who are from the southern states to gather more information from EHDI or your individual states and then tomorrow evening, if you know any Black or Brown professionals who work in EHDI, please encourage them to come to our brunch and mingle. For Black and Brown professionals to get their input so we'll be working with them, as well so we're trying to figure out how to support those individuals who are working in the southern states and then we're going through that program, as well. Sorry for that really long introduction but there was a lot there.

>> My name is Lee Burnett. I work for the state Department of Public Health newborn screening program. I've only been in my role for a little over a year and I have met two of these ladies through the REAL@Shaco a year ago in December. I'm a sponge and I'm just here to soak up everything .

>> Hi I am Mary Ellen Wigam I'm the Alabama EHDI coordinator. And I work with Lee and so my goal is to soak up as much as we can learn about early intervention so that we can collaborate better and learn more how to work together. So that's my goal for today.

>> Sorry about the mask, I didn't have a clear one and I didn't bring my own clear mask today I apologize for that I'm Roxanne I'm the director of education low incidence outreach we serve 0 to 26 we have a School for the Deaf but we do outreach so we go to all the states that don't go to Michigan School for the Deaf so I'm here to learn. Never stop learning. So thank you.

>> I'm Suzanne Bondolan I'm a clinical audiologist at Children's Hospital of Philadelphia so a colleague and I drove out yesterday I have friends in the area because I actually did my externship as an audiologist at Cincinnati children's. So it's like coming home.

My pronouns sorry are she/her/hers.

I work clinically but my non-clinical work over the past few years has really developed into building a family support program where we can leverage the influence and power and funding that chop provides in order to help families connect and I'm really excited to be here and learn what I can about the world where I don't go, early intervention, and how to support families in navigating that and getting the most out of it. So thanks.

>> well, again my name is Brenda I'm the room moderator. But I'm also the Minnesota Guide By Your Side manager. And so I'm a parent. I am a grandparent and I'm hard of hearing myself.

But anyway, our program, you know, again, by the we get the referrals, I should say at the time we get the family referrals, the family is also referred to early intervention. And so there's only -- there's times if we connect with the family and early intervention hasn't already been in touch with them, then we can make that additional referral. We just help to make sure that the connections are made.

And so I'm always anxious to hear, you know, how other states address -- because we get a lot of families that say, my baby is two months old or six months old, why do I need early intervention in the home? So it's just to help explain that. Yes.

Welcome, come in.

>> We need more chairs. We can move closer together. Scoot together.

I'm not trying to overlook you guys who just came in. I want to make sure I'm not ignoring you. I want to give you a minute to settle so you don't feel appreciated.

Okay. For some reason my computer is frozen. Bear with me a moment, please.

Would you mind figuring out the computer? For some reason something is frozen and I'm not able to advance the slides.

So we're going to continue anyway.

>> It's working I think. If you've got the clicker.

>> When I clicked the laptop, it didn't advance. It's frozen.

>> Maybe the laptop needs a hearing aid. It's not being able to communicate. What can we say.

>> I tried everything.

>> There it is.

>> Oh. Thank you.

>> I've got the magic touch.

>> Maybe I didn't try it all.

Okay. So I would like to go ahead and introduce myself at this point.

My name is Betty. This is my sign name.

And first and more importantly about myself, I'm a mom. I have two transgender children. And it's interesting that my children both came out recently within the past three years and that was the first time that I really thought, okay, this is how hearing parents feel when their child has a different identity from what they had.

I know it's not the same.

But it's similar enough feeling for me.

And honestly, I went to Graduate School while my kids were babies.

I graduated, let me think, I think they were 3 and 5.

So I'm learning about child development.

And watching it happen.

And now my kids are older, they are adults.

Also, I'm a researcher.

I just finished my PhD Program. Just graduated in December. Congratulations.

Thank you.

My dissertation topic was how hearing parents with Deaf and hard-of-hearing children can start to understand what Deafness means or what being Deaf means.

And so this presentation is from my dissertation to really look at how to understand the meaning behind all of this.

But also it's a little bit of a different perspective.

I'm also an early intervention provider. I was at the New Mexico skoov for the Deaf for 15 years. I worked with Stacey there directly. We worked together for how long was that.

>> I would say seven years.

>> Yeah, right about seven years.

Wow.

So that's fun for me that you're here. And also my heart is in the work with families.

And the relationship that they have with their children. That's a key part of me and my work.

And sharing things about myself.

Because it's important for you to understand where I'm coming from and understand my perspective.

My Master's Degree is in Deaf Ed and early intervention.

From the Utah State University.

And at that time it was a bye bye program (phonetic) so that's my ground.

Any questions so far?

So you can tell I'm a little loose with the agenda. I'm not strictly following it.

But I want you to feel participatory in this learning

I am not here to preach anything to you. I want this to be an experience where you think, you take in some information, and then you question your thoughts, beliefs, actions. What you do, what it means, how it applies.

So if you need more time to discuss something that we are discussing, let me know.

And this is the agenda for today. We'll talk about primary goals.

And we'll introduce the concept of social construction.

We'll also talk about disability and what that means.

And then thinking, okay, what we say and how does it impact the people that we say it to. And then working on our words and actions. And how they can create barriers. And then we also have to think about your programs. And your communities. And what barriers you have. And how we can dismantle those barriers.

Are we good? These are the goals that I listed on the EHDI website. And we will discuss all of these things.

But again, it's more about your learning and what you want to take away from today's session.

Are there any questions about these goals? Okay .

Go ahead and read this slide and then we'll discuss it.

>> Give me a second to wait for the microphone.

>> I was wondering if the slides are available online?

>> I told them that they could share the PDF of the slides so hopefully they are available.

>> Okay. I didn't look.

>> Yes, this is Brenda, I just know because I'm a presenter in that we have to download our PowerPoint on to the EHDI website.

So if all of them are on there -- and I'll double-check it to make sure. But everyone is supposed to download their PDFs on to the website or you can see it on the see event event app.

>> I did do that. So it should be there. So I did upload them, fingers crossed. They are there, we have proof right here. So do you want a minute to find them, find the slides or should I just go ahead?

Most of us are familiar with the medical model and the medical perspective, right? Honestly, the most widespread model is the medical model.

I'm going to back up just a little bit.

When I use the word disability, it has different meanings. Okay?

So please understand that I never mean offense.

Disabled could mean a different way of doing something.

But the medical model perspective of disabilities, they look at deficits.

Right?

They try to diagnose.

There are many things that we can learn and be viewed from the medical model.

My kids came out and many people thought, oh, something is wrong. They are bipolar.

Right?

Instantly there was a medical diagnosis for what was going on with my kids.

And some people will easily say, ah, it's just a different way of life. That's the social model.

So these apply to many different things.

Many people might feel Deafness is a disability because if you look at the definition, if you look at medical deficit for diagnosis for levels of hearing loss, that's one way to look at Deafness.

And in the social model, really we focus on diversity. It's different.

It's a different way of being.

It's a different life.

Any questions about that? About these two concepts?

.

>> I'll let you take a look at the slide.

Are we good? Everybody has had a chance to see that slide?

So Holler et al. Did a research study with occupational therapists and they surveyed these occupational therapists perspectives on the children that they worked with.

And they found that those who came from a medical model perspective, perhaps unintentionally but looked down upon and saw their children as inferior due to their disability.

But those therapists who had more of a social model perspective had a more positive outlook on the children that they worked with.

The idea of them having potential as opposed to a deficit.

That finding was interesting. Maybe you might be wrong to believe it doesn't have implications but those different perspectives really have grave implications when we're working with children.

And that's why I wanted to solicit this concept for purposes of our discussion. It may be unintentional. I may -- I'm assuming that no one here is intentionally harming children, right?

We're trying to support families. Of course we want them to succeed.

But sometimes our perspective, where we come from, creates barriers to that.

And that's why we're here.

Is to really reflect on our own perceptions, our perspectives, and are we creating barriers in the systems that we work within?

All right. The social construction model, it's a little bit different. It's not just seeing through a diversity framework. But it's recognizing instead that there are multiple factors that do create barriers. And those barriers then create disabilities for people.

That then means that we create disability. And in fact, that is the case. We do.

Some of those factors we can't change. But others we can.

And we'll have more discussion around those specific factors that we can and can't change. But this topic is the focus of our discussion here today.

Right?

We actually create disability collectively.

As a society.

It depends on the barriers that we create or choose to dismantle.

So for example, we have the microphone so that we are able to use CART /captioning. We have signing individuals, we have individuals using their voices. So we have established access. In our space.

So who here has any disability? Right? Really all of us are on a level playing field.

Because of that access.

So that's an important component. And I'm hoping that we can keep that in mind throughout our discussion today as we move forward.

All right. So I'll give you a chance to read this slide again real quickly.

Are you familiar with who this is quoting, the author of this quote?

>> No.

>> Gross.

>> Is it Mary Ellen?

>> This is actually a quote from a book.

>> About Deaf people on Martha's Vineyard.

>> Yes.

>> Yeah, I think it was Mary Ellen Gross but it talked about the Deaf Community on the island of Martha's Vineyard so it's familiar to me.

>> That's right, do you want to expand some more on that, Stacey, or do you prefer that I would.

>> You can.

>> Absolutely.

>> So it happened there were a lot of Deaf people that lived on the island at that time.

It was congenital Deafness that existed on the island for generations. And the people who resided in that community all signed. Whether they were Deaf or hearing. Regardless.

So everyone, if they had an uncle a family member a cousin, you name it, someone in their close knit community who was Deaf so everybody just signed as a result.

So in that society and again it uses the terminology handicap but the point remains the sense of disability depends on the context or whether anyone is disabled.

Even someone who wasn't from there, they would think, okay, Deaf people have a disability and the people residing on the island would say not at all I just happen to be Deaf but we all use the same language so it wasn't disabling.

With that in mind, what I would like you to do is take part in a quick write is what I'm calling it.

I'll hand out some paper or you can use paper you brought with you. I happen to have some colored pens because I just really love seeing a variety of colors. But regardless, I'll hand out some pens and paper and I think we'll write for roughly 10 to 15 minutes. On just your thoughts after having read this quote. Okay? So just head into that.

>> Uh-huh.

And I do want my pens back.

(Chuckles).

>> We're going to steal them. Just kidding; just kidding.

>> I would be terribly sad.

>> Don't worry.

>> It is fun to use colored pens, everyone, right?

.

(Standing by).

>> We have roughly 2 minutes remaining in our allotted time but it seems we have a couple folks still writing, would you like to take those 2 minutes or do you feel like you're at a stopping point? Okay. If we are all at a stopping point, we can get moving again. All right. Understanding is that we occupy a safe space, are there any thoughts that merged for you that you would -- emerged for you that would you like to -- that you would like to share?

>> I'll stand to make it a little easier.

It's fascinating to me. I grew up in a hearing family.

This is Deb. I'm the only Deaf person in my family.

And then I have a Deaf daughter and a hearing brother. But anyhow, my brother grew up having me as a Deaf sibling. And it was just a way of life for him. He didn't think much of it.

Recently my brother married a woman who is -- who experienced some hearing loss. But she fully functions as a hearing person in her identity, in her communication. She teaches music, you name it. But she has a progressive hearing loss.

And her mother also has low vision. And my brother is used to those differences. Having to look her in the face and make eye contact. But I wasn't used to that as a sister-in-law. I would have to get used to how to communicate with her. But he knew what to do because he grew up with me as a Deaf sibling.

As my sister-in-law's hearing loss progressed, she doesn't sign at all. My brother finally told her, it's time for you to take an ASL class. You need to learn ASL. Because we need to make this as possible for us to co-exist without struggle. To learn to sign and everyone will have visual access. And my -- my sister-in-law was really dumbfounded by that and questioned that.

She can't hear him even though he's screaming. He said no it's time for us to change our mode for communication, our family setup in terms of communication.

And she realized, okay, we have to change how we communicate in order to interact with each other so that we can have -- just get along in our daily lives, our routine. She was very quick to suggest technology, implants, hearing aids, but instead changing our language to make our family work now is where that came from and it was really interesting to just watch that dialogue happened. It really coincided with this quote, his perspective and changed her perceptions of her own progressive hearing loss, as well and she was asking me things like how do you know if a timer goes off? In the home, how would I know. And I say, well, I just watch it. I watch the timer, I keep my eye on it, I don't rely on the alarm or the beeping of the timer. And different strategies that come into play, it's just a way of life. It's not like I have to modify things in order to hear them. It's just been a real learning journey for her to go through and for my brother, as well, it just made me think how much that sort of goes along with the quote.

.

>> It's funny, Deb, that you mentioned the timer device. Because my timer on my watch went off while you were talking because I had set a timer for 10 minutes it just vibrateed that's how I knew it was going off and I was like, okay, time for our writing is done. But thank you for sharing that, Deb .

I think it's so important to recognize that if something is not viewed or viewed as a disability it really depends on a situation that a person is in whether it is. And it can -- it could change over time. That could evolve in either direction. So thank you for sharing that. Anyone else who wants to share something they reflected on.

>> I've got different thoughts racing in my mind now based on my experiences, based on what I've seen and also based on families that I work with. But I often think of disability when accessibility is taken away. And that's when a disability happens. So -- that's for either group, it's not necessarily for the Deaf person it could be for the hearing person, too, if you don't have access to something, you have suddenly become disabled. So to me it's related to accessibility and lack thereof.

And it is all about perspective.

It is your perspective on what disability means. And yours may be different than mine. So for example, I remember a person saying oh well you're disabled, well why -- because you're signing I said well how many languages do you know and it was only one. Well I happen to know two. And therefore, you are disabled and not me.

I can still read and write and you can't sign back to me so therefore you are disabled not myself.

Knowing two languages gave me an advantage in that case, so it all depends on perspective.

It is also about mindset, as well. What is typical or normal to you may not be normal to another person. What I think is normal may not be what you think is normal. So we're often stuck in our own perspective, too, instead of thinking -- and instead what happens is we think of my perspective is the right one.

We never think what normal is for one person isn't nevrl what normal is for us.

So disability is really up for interpretation -- not necessarily -- it's really on interpretation based on mindset, perspective, and what you've witnessed so people view me as disabled and often people don't -- Deaf people don't view themselves as disabled. But for me, it's just a way of life. So I don't think that I'm disabled, I tend to think the person talking to me often is disabled.

And often people think it's the Deaf person who can't communicate with them but it's they who can't communicate with us. Again, it's all about perspective.

>> Betty here.

And the important aspect is either perspective is not bad per se or not wrong per se. Let's see. It's what's true for you for that particular person in a particular setting.

.

>> I do also think it's bad when someone becomes language deprived and that's when the perception can become the barrier.

>> Sure and discriminatory, as well, certainly.

If you create more barriers, then that's discrimination clearly, yes.

>> Exactly and that person does in fact become disabled because they don't have language.

>> You bet.

>> It's not because they can't do it, it's because the environment they were in deprived them.

>> It's interesting that you mention that one family that I interviewed for my dissertation, the dad has a Deaf child said he was searching for resources. And wanted his child to be bilingual, bimodal. . But he couldn't find resources that he wanted.

He said I'm noticing that the system is disabling to my children.

.

>> That's right.

>> Because he simply couldn't get access to resources. So absolutely.

I'm right on track with your comment, Stacey.

Are there other thoughts, other reflections? Yeah.

>> I just wanted to touch on what she was talking about.

My background is in sociology. I have a Bachelor of Arts in sociology so I understand the social concept of it. And then I also have a degree in nursing so there's the medical side of it but I wanted to read to you what I wrote.

As a hearing person who can walk, talk and earn a living by the medical community, I am not considered disabled. However, if I cannot communicate with my loved one, friend or co-worker, who uses ASL, I am disabled.

So as society we need to focus on the ability rather than how it's done differently.

>> Thank you so much for sharing that.

Did you want to also comment.

>> If you don't mind I would like to add, too, I really appreciate your example of none of us in this room hopefully are disabled right now because of access. That was a huge -- that's a huge impact. Because I'm hard of hearing. And I rely on everything here. So some of the things that I wrote -- and I'm thinking from a family perspective, I'm thinking of my daughters and my grandson, sorry. It's emotional. Anyways. How can we better write social goals in the IEP? How can we make that more measurable and successful? Right? That's what I want to learn. And that's what I want to pass onto other families. Let me see. Some other things I talked about. Oh. You know, it's just like language, I would like to see more professionals, whether it's the medical professionals, providing to the families all the different options so that the families can choose what works for them. You know, you hear so many professionals, yes, you have to have this technology. Or you have to use this language. Or don't use this language.

All of these variances.

And so it's like, no, it's the family who knows their child the best. So they have to pick what works for them.

And it's okay if they pick something that doesn't work.

So that they know what other options are so that they can try something else. Right?

And so those were some of the things that I put down.

Sorry.

>> Thank you.

Hang on one second. I just want to comment before the next comment.

Thank you, first, for being open and showing your vulnerability.

I feel like all of us have felt something during this session so far. For being -- thank you for being so honest.

And it's interesting in regard to your comment related to choices, you said choices.

All families in my dissertation when I surveyed them, they said Deafness is really signified by limitation.

So what I understand Deafness to mean is when you start with something very minimal and you expand upon that, they see that there are so many limitations in the beginning and then think, okay, there are -- there were a lot of barriers and now we've been able to overcome those barriers. So this topic is more about where the limitations are and then identifying who set those limitations. And how we can work around those limitations.

And instead of choices I prefer personally the word opportunities rather than options.

Because when you think about parents, we don't want to limit their options. That typically forms a binary structure. They could want it all. Or want whatever is right for my kiddo.

I do as a parent.

I want whatever is going to work.

I don't want to be stuck with one choice and we don't even know yet what's going to work for them. Do you want to follow up with my comment? Sorry.

>> Thank you, I like that, I love the choices of words.

We try to provide to the families unbiased choices of words. For me, I don't -- I personally don't care for the word disability. I don't think I'm disabled. But I use the word challenge. I just have extra challenges to get the access I need. So whether a child has a different condition or syndrome or there's all of those different labels, that's what I use to families.

But I really appreciate that opportunity versus options. I like that. Thank you.

>> Thank you.

>> I have a similar story I think as far as being Deaf or hard of hearing, I grew up in a hearing family, my husband is hearing, my kids are hearing, my brother is hearing. But I would say I think it's important, too, that there's no wrong or right way to be Deaf.

So you know, we all kind of bring a different uniqueness to the table.

And I think the biggest thing for me was growing up in an environment that I was the one and only that I knew. And then when I had the opportunity to meet someone else who was Deaf or hard of hearing, I was like, oh, like it was just kind of a relief to know that I wasn't alone in the process.

So when I think about that, when I met someone else, it also helped me with my advocacy skills.

Because I was able to maybe share with others who may not know and not to any fault of their own. But just for example like the captioning, oh, could you turn the captioning on?

Because that really helps me.

So things like that I think if we can empower the advocacy piece on, we live in a very imperfect world. And that's just where we are.

But if one person at a time, if we can instill that, maybe we can create more inclusive environments moving forward.

So -- but I liked your word of opportunities, as well. I think that's a great choice of words.

.

>> Thank you for clarifying that.

The idea behind advocacy really is -- so in my perspective, the word I use is ally.

You see my rainbow on my watch? I try to have different rainbow things to show that I am a person who can be relied on. And you can be safe with me. Where is my phone? It doesn't matter.

On my phone I have a cover that says proud ally.

That's it right there.

That's hers.

But mine is similar.

So you're right. It's important for us to advocate, ally, whatever word you want to use, it doesn't matter necessarily.

But we need to make sure that we're recognizing each part, each barrier, that we're creating or dismantling.

I love it. Love it.

Please, CART, add the captions or whatever you need, whenever we need anything.

I think to myself, okay, oh, wait, I forgot to add my pronouns when I introduced myself.

So I'm not perfect.

But I'm trying to become more of an advocate, more of an ally.

So there are little things that we can do, each of us, individually, to become an ally.

Thank you. .

>> This might be common sense to some, I don't know, but in our program we really strive to make sure that the families are connected to the Deaf Community. And we are birth to 5. So it's very young.

And it's not forced on them. It's done very naturally. We always have a Deaf adult with us and we use that all the time, there's no one way to be Deaf.

We want parents to understand that.

And I love the example of the timer.

Those are the type of things that you know when the families are connected with these Deaf adults and these little conversations happen that they are like, this is okay. You see it in their faces, in their body language. And it just is a beautiful thing to watch. I also love the children seeing a Deaf adult. I think it's very enlightening I just have to share real quick I was at a visit in a rural area two weeks ago the family has done a beautiful job creating a bilingual home and they are doing it without a Deaf adult really close, everything is virtual. So I brought a Deaf friend of mine with me.

I asked them, I said -- this child a young, he's 3 I said I am -- is it okay if we talk about who is Deaf who is hearing and the mom asked who is Deaf and he raised his hand, I am when my Deaf friend raised his hand his face I won't forget it it's the first person he's seen I think he's still trying to figure out about me but it was just such a sweet situation.

And I just think it's so important. We take the families who are, you know, still traveling that journey and trying to decide what to do but exposing them to all of it so they know that those opportunities are there and they know where to connect. And then we're -- I think as a hearing person, I feel like I'm the bridge to support the families, answer their questions and connect them with the Deaf adults.

>> Thank you.

I also want to add to your comment, there's not one right way to be human.

So if a person feels within themself that they are disabled, if they want to call themselves disabled, that's how I identify, some people prefer that.

And that's important, as well, we want to make sure that we're recognizing and respecting peoples perspective of themselves. And the most important part is that we're not creating barriers.

We don't create barriers. Okay? Any other comments before we proceed to the next topic?

Okay. We'll move on.

So this is a busy slide.

I know there are a lot of words up there.

There are a few examples here on this slide of how these systems, these topics, create barriers.

And they cause disability.

And they definitely permeate stigma.

A quick example.

Social media.

You've all seen it. All kinds of views in regards to Deafness on social media.

Right?

Information about signing. Information about babies getting cochlear implants, all of it.

Does it tend to perpetuate a specific perspective? It does, right? And it's out there on the ether. And almost everyone has access to that information.

So just for a minute think about something that you've seen on social media that you've felt this is perpetuating negative stigma.

Can you think of something? What comes to mind?

>> Appropriation. For example, with signing --

>> So for example, cultural appropriation regarding signing. I've seen many hearing people teaching sign language.

We're not against hearing people learning sign language. We greatly encourage it. But leave the teaching part to the Deaf and hard-of-hearing people. But there are so many hearing people out there who are making a lot of money teaching erroneous signs. And then Deaf people, when they try to say, hey, leave it to the Deaf people, then there is protest against us and they feel victimized on social media but it's not about them.

They are using our language for profit instead of encouraging those people that they should be following in the Deaf Community to teach sign.

So I feel like that becomes a barrier when you use the language for profit without recognizing what they are doing.

>> And I tend to assume the best from people, right?

Always assume good intent. So we're hoping to encourage more people to learn sign language. Maybe that was their intent of why they were doing it?

But at the same time, it's important to be humble enough to recognize, I'm sorry, I should not be doing this, this is yours, this is not something for me to take notice.

>> Well, yes, when Deaf people try to call them in and tell them that it's inappropriate, they become a little more belligerent. And then state that Deaf people are against them. And they take that victim mentality.

And that's where the battle occurs. And then people -- their followers pity them.

>> Okay. I'm going to back up for a second. Social media is the worst place for people to act like really nice humans.

It's the worst place. Right?

People just say whatever they want.

There is no filter. At all.

They just put it out there, whatever it is, and I often think once it's out other people want to respond to that. So then they say something equally erroneous to get comments.

So maybe I shouldn't have brought up social media to start with.

But really it's something that's so, so delicate.

Because when you think about everyone having access to it. And you just post something, and you have no idea where it goes, there's no deleting it for real.

So . . . it's really -- it's a hard place. But at the same time there's a positive --

>> But at the same time there's a positive perspective because families do actually learn about Deaf culture, Deaf Community and sign language through social media and I'm thinking specifically of our rural families. So it can be used for good.

>> Exactly that. There are always pros and cons to everything, right?

So we need to figure out what we say, what we perpetuate in our posts.

I'm sure you can think of examples for those of these things, right?

>> In the home especially with my dad who hates captioning on TV, you know, he's watching TV. And the captioning, he just hates it. Wants to turn it off. Turn it off. Hates the captioning on.

He wants -- I'm like, Dad. Come on.

He's in his 80s, okay, there's no excuse. He lives with me. And my kids.

So you know, there's that. Another example in the home could be that, you know, the captioning is not on the TV, like I said, that's an example.

>> Right. What are other examples that you can think of? Maybe -- one story that I heard from another family was they said -- this was a while back now.

When their kids were younger.

They would watch a show. And one of the characters was gay.

And one of the parents said, oh, that's gross.

And then later, their son came out.

So the feelings or topics that come up we're not necessarily going to expect.

So we need to discuss these topics. Because I think what happens is we don't know who in the room we're offending.

So it's really most important to recognize how to be more inclusive in general.

>> Just looking at the grid you have up there, I look at church. And my family every Sunday morning we are at church.

And in Sunday School particularly, one of the Sundays I went to Sunday School, and my mom came in and she said, come here, come here.

I went out and went out to the congregation area. And the pastor was there and he was standing and I had no idea what was going on. And I think I was at that time maybe -- I had to have been 7, maybe 8 or so.

And they were all standing in front of the altar, big congregation, mind you. And someone came down. They were talking. Again, I had no interpreter, I had no aeshtion I had no idea what was going on. -- no access -- and my mom signed a little bit. She didn't sign great. But she signed a little bit and she went over to the pastor and she did this to me and I'm like what is happening the pastor did this to me, I'm sorry; I'm touching you I'm all over you and I am like what is happening. I'm looking around.

And there were people just bawling their eyes out and crying and telling my mom, don't ever, you don't ever need to do this again, this is me telling my mom, accept me for who I am. I'm Deaf. This is me. And then Mom finally started to realize.

And then she was a better advocate for me. We got an interpreter for church.

And we also had an interpreter in Sunday School, too.

So the time changed around for me in that situation.

>> Let me clarify, this person is trying to heal you?

>> Yes. Their hands were on my ears like this and they were speaking and I was like looking around thinking, what in the world? My Lord.

I was like, what's happening?

And you're lucky that no one didn't punch you in the face.

Because for some reason people want to touch me in the face for whatever reason, grabbing my face, doing this with my face, you're lucky that didn't happen. In today, today's world.

And again, I was 7 or 8. I wasn't the best at speaking my mind. I wasn't able to. But she did eventually was able to teach me how to advocate for myself I'm like Mom, is this what you mean by this and she was like you got me, you're right. I never will do that again to you.

So that immediately popped up when I saw the word church up there on the grid.

>> So the opposite side, one of the families in my dissertation shared that they were able to go to a signing church.

And it was such a great experience for them.

Because there were many Deaf adults there as well as families with Deaf and hard-of-hearing children. So they could all play together.

And everyone had a different experience.

And it was a beautiful opportunity for the family.

So it can go either way. Right? .

>> Yep, you're right.

>> So all of these things can either be a barrier or get rid of barriers or destroy barriers.

>> I would like to add a little bit back to the idea of church I was in the South so keep that in mind.

And oftentimes interpreters at that time were not certified interpreters. Maybe they had taken an ASL class. One or two levels of ASL.

So they were pretty superficial in using their language. Vocabulary was limited.

And I remember sitting and watching this interpreter at the church. And I didn't understand what she was signing. There was so much information that was missed, so many omissions. And I again from the South but -- and there's just a lot of pity and God bless you, that kind of attitude back in the South back in the day. Just wanted to add that.

>> I understand.

>> And I'm looking at the grid related to mental health.

How many of you during COVID had to stay home with your own teenagers?

So that was really a challenge, as well.

Especially for our family.

Because we do have a Deaf and a hearing. And they each missed their friends, their community.

We do live a bit away from other Deaf people.

Other Deaf friends for my daughter.

And so she kept wanting to socialize with her friends and I tried to find you know a therapist to work with her, as well. And that was nearly impossible. And now it's harder than ever to find someone who are willing to work with teenagers.

Add to that, the signing accessibility.

So that adds to it. I can think of a lot of examples of almost everything in the grid. I could talk all day. But I don't want to take over your time.

>> Well, this is the point of this slide. Each of us can have an impact on each of these things. And that's what we're trying to figure out. What can we do individually to impact all of these things in our area, in our world, in our community.

Are there any other comments before we move to the next slide?

>> So again, the grid that we just looked at, the variety of domains that we discussed, certainly that's not the extent of them.

There are a great many more than what was listed on the slide.

This quote goes to the importance of understanding. Not just internal but external factors in creating disability. How they interplay.

In either creating or dismantling barriers.

I find this very interesting.

Because I've talked to a real variety of Deaf people. And one person that I talked with one time said I actually feel as though I have a disability.

Because of, you know, X, Y, Z. And she just listed a bunch of different scenarios in which she experienced discrimination. Or what have you. And she felt like okay, I'm not on a level playing field.

I feel like there were barriers that I encountered. And that was her experience. And I have respect for that. But not everyone feels the same way.

I, for instance, wear eyeglasses.

And you know I don't care that I wear glasses. And most people don't care that they wear glasses.

But interestingly, one of the families that I work with happened to be from another country. And they didn't want their child to wear glasses.

And it made me think, huh, you know, maybe that's a cultural thing.

You know, maybe their experiences, their perceptions were different than my own and it's an important thing to recognize those differences.

I'm trying to think of the right phrasing. Some of what we believe internally comes from external influences to our ideologies.

And some of the work that occurs inside of ourselves has implications on a societal level.

But each person is their own sort of mini society. Does that make sense? And it's complicated when you think about it as a web like that.

But at the same time, it means that we actually can improve upon our society by reducing barriers.

Right? We have that capacity. Because we are a part of this web, this interplay.

And so this also gives me a lot of hope.

Positive outlook. That we can really make some strides in this. So that's why we're here.

And it starts with just the thoughts that you've been sharing.

And then those translate into actions.

Yeah, Brenda.

>> This is Brenda. I had a very interesting situation that happened to me this morning. I attended a quick Training Session. And when I walked in, there was only like five people in the room.

But they told me that they had a -- an interpreter for me.

And I was like, um, I can sign but I prefer CART.

But you know again, it was just that assumption. Because I had marked down that I was Deaf or hard of hearing that they assumed that my first language was ASL. And they provided that.

But that wasn't my main mode of communication. And so that really -- it made me sick back and I was like, wow, you know, -- sit back and I was like wow that's another area especially at a conference like this where we do provide access to everything, that was just eye opening for me to see it from a different perspective.

You know, that, again, they just assumed I was going to use an ASL interpreter.

And I told them at the time I said, no, I'm fine, I'm lipreading you, we're close enough. It's a small group. But also -- it was just -- I don't know. It just made me stop and think.

>> Yeah, go ahead.

>> This makes me think of a time when I went to have surgery. I had hernia surgery performed. And I had requested an interpreter well in advance but I did show up and none was present.

So I asked where my interpreter was because, you know, I was going to be under anesthesia.

And they said, no, no, no, it's fine, we've got pen and paper and I thought you're going to be gassing me. How do you expect me to communicate with you when I am out of my element. I'm just out. Right?

So all groggy and like I can't write.

So honestly, I really -- well, that was a little bit of an argument.

But excuse me; not bringing in the interpreter and expecting me to write when I just come out of surgery. That's ridiculous. Funny, but not funny. At the time it wasn't funny. It's funny now.

>> Right, exactly, how much red tape would you have to go through to reschedule if you didn't proceed on that day it's like give me a break.

>> I refused to schedule again, I mean, I refused to proceed with it that day until they scheduled.

>> Yeah so you just put up with it.

Yeah.

>> It's unfair to think. But had she been from a non-English speaking country, there would have been an interpreter for that language.

>> Right.

>> I'm a recovery room nurse, or I was. I can understand the difficulty in communicating with someone, No. 1, who doesn't communicate in the same language I do. And then, two, in a post anesthesia induced state.

>> You know, it's a very interesting point that was brought up.

Because I feel like generally speaking, our country has made an effort to be more inclusive.

Has tried.

>> Not for me.

>> Not for me.

>> Yeah, so to speak, right?

>> But -- and I should back up.

Has made the effort for people from other countries when they speak a foreign language.

>> Okay, thanks for the clarification. Okay.

>> Right, exactly.

White privilege certainly is an aspect of that.

But that's an interesting part. Right?

Of the variety of different languages that get spoken in our country. People go to universities to learn any number of languages. And it's kind of cool if you know a number of different spoken languages.

But there's not the same status for learning ASL. Or other manual languages, other signed languages.

That being the case, it has improved certainly since you know 1969 let's say. I mean, there are --.

(Chuckles).

>> I know, I see you Stacey. There are universities where sign language is studied. I'm working at UConn now. And they have people who are studying Jahan knee sign language. And -- pardon me. Shanghai. Shanghai, thank you, Shanghai sign and any number of international sign languages .

The variety of international sign languages that get used are being studied at UConn I think my goodness I had no clue that was happening until I was exposed to it.

So there are efforts being made to improve. Disney performances are being signed in ASL. And there have been strides that have been made, which means that we need to continue those strides.

Continue to improve.

When we look back at where we came from, we can certainly see that progress has occurred. Slowly. But surely.

And yet slowly.

Which means that we must be even more vigilant to perpetuate that progress.

I was talking with a colleague recently. And I was just explaining why I went back for my PhD.

And why I wanted to study the things I'm looking at.

And let's see, I want to say that she's hmmm in her 60s, there abouts.

And so I was explaining my excitement and my enthusiasm around what I wanted to study and share information with all of you that I was bringing today and she kind of made this thing like oh, okay, okay, you know.

And I was a little bit put off by that. I went, wait a minute.

She said, well, good luck.

You know, I've been working in this field for 40 years and it's the status quo.

You know, improvement takes time. It's just slow going.

However, if your internal beliefs are that you really do want to see those improvements take place in terms of you know, removal of barriers and improvement in access, so people can feel like their human experience is unique and valid, we have to stick at this. We have to continue this effort.

So at that point I think we're going to pause and take a break. I think it would be nice for all of you to have a bio break. Get a drink.

So let's come back at 2:30 -- I'm sorry; right now it's 2:30. We're at the midway point.

Can we agree on a 10-minute break, does that work for everyone? All right. Let's go with that. And we'll see you back in 10.

(Break.).

(Standing by).

>> Hello, everyone, are we ready?

I'm going to go ahead and start again.

I chose these pictures with intention.

Do you see the glasses? Most of us in our society wouldn't think that this is a disability.

However, the person might think they are disabled.

I don't know what their vision loss or level is.

But if you don't have access or your access is denied.

Then that may be disabling. But many of us don't even notice when somebody is wearing glasses or not, right? There's such a -- they are such a norm in our culture. It's like having a different hair color. And then in the middle picture we have a person who is a wheelchair user.

Is that a disability? Or not?

.

>> Well, to me it's not. But it's not up to me to decide. It's up to that person, isn't it?

>> Bingo.

However, I bet that person would say yes if dot dot dot.

Yes, if there's no access. Yes, if there's no ramp. Yes, if there's no curb cut. Yes, if things are placed too high for me to be able to reach them, all of these situations there are times that are disabling because of the context or environment.

And it might not be a person identifying as disabled themselves, but they will feel the situation itself is disabling for them.

But honestly, the person honestly could have maybe just had a knee replacement, for example.

Or a hip.

(Chuckles).

>> Maybe it's a temporary user of a wheelchair.

So during that time I bet that person experienced a lot of areas if they are used to living without needing a wheelchair and now there's this time that they do temporarily need one. I'm sure they would be able to identify barriers.

So this is a funny example, my friend came to visit. And she typically is accident prone.

She was running and just fell and broke her kneecap. Uh-huh.

Two months later she came to visit me. But she still -- she still had her brace. And before she came, she broke her toe on the other foot.

Yes.

So she came to visit me. And she wanted to go see Boston.

And I'm like, okay, let me figure out how to find a wheelchair. I borrowed one from our church. And it was terrible.

The wheels were small and really hard.

And all four wheels were really small and then you know Boston is full of cobble stone streets, right? It was the worst experience. And the hills. Ugh.

But that day I often felt, okay. These are things I have overlooked I don't know how many times.

I didn't have to think about it before.

So that was a good opportunity honestly. That's why I'm signing today.

This is a good opportunity for you who don't sign to have the perspective of, okay, I need to depend on interpreters who are working for me.

You're not getting the information directly through me.

Or from me.

So that's a reminder for you that this is a different situation.

And hopefully it's not a barrier. Because we have interpreters.

However, it's important to recognize there are many situations that we just don't even see the barriers.

Comment?

>> And we can debate all day long which disability is better to have but blind people prefer being blind they would rather be blind than Deaf because they can hear everything Deaf people say I would rather be Deaf than blind because I couldn't see anything blind. I remember my niece is Deaf she was young maybe 6 or 7 at the time and I happened to go to the nail salon.

And my niece was standing there and happened to see who was coming in, who was this person was a woman who had an orthopedic shoe that was elevated, one of those elevated shoes. She had quite a gait -- quite a limp and my niece said, oh, I'll pray for her -- I'll pray for her. And I thought -- it caught me off guard. She said she has a hard time running she can't walk and she can't run so my niece was pitying this woman that she saw come into the salon.

I said well maybe that woman pitys you because you can't hear music and you can't hear so maybe she's pitying you. So I turned the tables on her and that gave us a good conversation about perspective because I think you know you think being Deaf is better than having a limp she said yeah I would prefer to be Deaf because I can run and I said well maybe she prefers to have a limp so she can hear music.

So comparing disabilities was really interesting. I caught my niece doing it.

And you know, I would rather be in a wheelchair than be Deaf. Or I would rather be Deaf than blind. I mean there is no comparison. It is really all perspective.

But that conversation brings comparing disabilities to mind.

>> Right. And that reminds me of something funny I had a similar conversation with my sister.

And she has a sleep disorder. And she has a 3-year-old. So anyway, she has not left for years.

And she texted me.

Oh, wait, let me back up.

I have stomach issues. I'm nauseous all the time.

It's just who I am. I accept it and move on. Deal with it. But my sister texted me and she said, oh, I've been nauseous for two days, how do you survive? And I'm like honestly you get used to the body you live in, right?

And I don't know how you survive without sleeping.

So there's no point in deciding which is better or worse or playing the comparison game.

But when I thought about that I thought, oh that's interesting so my sister would come to visit and I was thinking about her sleeping situation in my house I was like oh could we make it darker for her, what can I do to help improve your situation in my space.

Other comments before I move to the next slide?

For this next portion, I want you to get the PowerPoint, this PowerPoint, read it on your own. And I'm going to show you which part I want you to read.

But do you have your phone, a tablet, a laptop or something to get the PowerPoint from, do you all have access to it right now? It will make it easier if you have access to the PowerPoint.

.

>> Do you want us to just read this?

>> Not yet. Don't start reading it. I want to make sure you have access to it.

>> Okay.

No, if you look at your event on the website. Yeah, it's on the website.

Or we can AirDrop it to each other.

Are we ready or close to proceed?

I want you to get access to this slide so you can read it but at the same time I want to explain what we're going to do before you go go ahead and read. We have four comments.

Within two slides.

And the four comments are from one family that was in my dissertation study. I want to explain what he with did a little bit in that. So my dissertation started with a survey. And we had 74 hearing parents. Who have Deaf and hard-of-hearing children.

Who participated in explaining their experience.

And they would jot down what they thought Deafness meant before their child was born.

And then what they think now that they have a Deaf or hard-of-hearing child.

And from the 74 participants, we had 5 volunteers to interview. Well actually more interviews. I chose 5. Whose children were under 4.

Because I really wanted to see the impact of early intervention on their understanding of Deafness.

So the interviews were lovely. The families shared their story and journey throughout early intervention and what that was like for them. And it was lovely.

But these four quotes were from one family.

And I asked them to explain their experience as well as explain what their perception of Deafness was. And some of the quotes really were in regard to their experience with a child and some were about their understanding of Deafness. Is that clear? So what I would like for you to do is I want you to read the comments that are on these two slides.

And then look at the word usage. What words are impactful for you, whether it be a positive or negative impact? And think about the context, as well.

Think about who is saying what.

And when we talk about the social construct where we had social media, friends, families, school, remember that grid? Now when you assess these comments, I want you to think about who may have said it in relation to the grid that we saw.

In regard to understanding of Deafness, does that make sense? And are these comments producing barriers or breaking down barriers? Or eliminating barriers? And if someone -- if you had to say this comment, how would you modify it. Or could the comments themselves be improved in any way? And any other thoughts that you might have had about that comment.

Do you need more paper? Or are you good? More paper?

>> I have a question.

I do think the people who wrote the comments themselves or People of Color, were they White? And the people who were talking with them? What were their demographic -- was their demographic information? Because I think that makes an impact on how we receive that information when we're interviewed, just that whole interaction, I'm very curious about those variables.

>> Thank you for that point. It's a good one.

These four comments are from one family. And it's either the mom or dad. Both were White.

Middle to upper class.

Remember, they volunteered for research.

And typically research participants are upper class, middle to upper class White participants.

So I tried to pull in people with other identities. But didn't have much luck.

So a little bit of context will be in the comments that we make. For example, the dad will say, oh, my uncle called me. So hopefully there's enough background there to be able to understand it.

>> I lost my train of thought -- okay. Those families on the grid, are there other families? Will we know anything about them or who are they? I'm just curious.

What I mean is out of those 74 families, are most of them White? Are I think any BIPOC families involved?

>> Most were White.

>> I was just curious.

.

>> I think we had 89% White.

>> I think that's pretty typical.

>> And I'm thinking about how to improve it, no, I appreciate your question, because it's important. And I realized that it's not providing all perspectives. And that's a weakness of my study.

I recognize that. And I'm thinking about how I could improve that for future studies.

But my study was posted on Facebook. And I asked for people to share it with their groups.

And I got the respondents that I did. But I need to figure out how to be more intentional in regard to including diversity. And having a more diverse audience. So thank you, I do want to clarify that for everyone. Okay.

Are we ready to proceed?

I'm going to go back to the previous slides so you can see the directions.

>> All right, everyone, it seems like some folks have finished up so I would like to get started again. All right. Do you have any thoughts that you would like to share about the first comment titled the extended family.

Yeah.

>> So I think education is key to any scenario when you talk about disability just like the word disability. The model that you have, you have the social model, the medical model but you're not talking about the educational model as well that's a whole other conversation because I come from education but I think the thing is people are just ignorant not because they want to be ignorant they just don't know so for all of these cases I saw I really think it's about educating people so they understand what the perspective is or what they should be doing differently.

And like this first scenario, not just DHH but there's other disabilities where people have come and they have explained how it feels like a loss in your life when you find out you have a child that will need accommodations because you have a picture of your child and all of a sudden something is given to you and it's hard to say -- that parent felt the grieving process a little bit in the beginning she jumped to the uncle who is great he hasn't digested this she has had time to digest and he's thinking empathy for her whether it's needed or not in that case I think in that case she just has to have a conversation like she's like he's a great kid, we don't see anything wrong. And he's like oh. So . . .

>> Sure, I agree there's multiple levels at play here, a lot of things going on within this comment.

And your comment about grief is an interesting one to me.

Because when my kids came out it was during COVID. Lockdown. We started -- people started saying how are your girls when we came out and started seeing each other and I was like well they are not girls and everyone had this reaction like oh, my goodness I'm so sorry.

And honestly I had some of those feelings, too, I had to grieve that process. I had two kids with a lot of similarities to me I was looking forward to them being pregnant and looking forward to many things but so many things I didn't realize I would have a sense of loss over.

Right?

However, the first time that I told one of my gay friends who responded with, congratulations, I realized, oh, this is permission for me to be happy.

I could be happy about this. Prior to that, I wasn't feeling happy.

I was feeling overwhelmed.

I was feeling some level of grief just trying to figure out, you know, everything. And it was COVID. Not -- you know, not to mention.

And there's nothing wrong with what the u-he will said specifically.

But it does perpetuate a sense of discouragement, I felt that my kid's identity and identity shift was heavy for me.

When sewn finally allowed me to celebrate that shift in identity it was a real weight that came off my chest.

And so certainly grief is real and grief occurs and that's a part of the journey. And I know that this uncle's intention was to provide some empathy in the situation.

But you know, if we say that to everyone and that was the only thing that we brought was pity or empathy to this type of exchange, we would be missing the opportunity for celebration.

.

>> As soon as I saw the word sorry, I was triggered because Deaf people see that a lot when someone is found out to be Deaf people react with that pity and it's right in your face and I'm sure as the parents are going through grief that pity is thrown at them for me that's triggering when I say oh I'm so sorry, I'm immediately triggered.

>> Right, yeah.

>> With me, to add to that, I was about 8 when my mother passed away.

My grandmother rather, my mother's mother.

So that was my babysitter.

So my aunt and uncle stepped in right away and said, we don't mind, we'll take care of Debbie.

The brother. But my aunt didn't want to. And then my parents felt a little bit stuck because there were no neighbors that felt comfortable taking care of me.

So I had a teacher who would also then become my babysitter during the week. I mean it was really nice of her to do that. But I'm like you know where are my parents, that wasn't explained to me.

Why was I no longer -- why was she no longer with my brother? And why is the babysitting situation changing. It really that impacted a lot of different aspects of my life. And I wanted to know more about that. So it sounds, I'm sorry, I can't, you know, I'm a human being here. So I can relate to that. It just made me think of what happened back in the day to me.

>> It goes along with the previous comment that was made about -- oh, my goodness, I've lost my train of thought.

Um . . .

It's important to recognize where people are coming from, as well, right?

And can we include this uncle in that notion. Calling him in. Oh, I know what it was. Your comment previously about we don't know what we don't know. Right? And I'm sure the uncle was simply ignorant, he didn't know what he didn't know. But we can provide that information, we can fill that in. And we can include him, call him into that awareness, yeah, other comments about this particular passage. Yeah.

>> I was kind of triggered by the I'm sorry, too, because people will say that to me, as well.

But I work with a lot of teenagers, as well, who are Deaf. And I think one of the things that we do is because as you said, people are just trying to be human. And empathetic. But you're going to get comments like that. So if we can almost put them in role playing situations where you see like well, what's that on -- what is that? Why do you have to wear that? And give them almost like an elevator pitch or a way to respond that in a non-threatening safe place when that comes up later on I feel like you can respond better to that and educate in the process, too. I think that's just another way to be able to handle a situation that can be difficult.

>> Right. And I feel like this is in fact a little bit what you're talking about, it's like, okay, this is fine, it's awesome, it's great, it's just a kid, take it as it is. Thank you for sharing that. Yeah, we definitely can encourage and educate and improve any given scenario that we encounter.

Other comments about this first quote? Okay. Let's move on to the second.

A little gesture. Any thoughts about this one?

>> This is Brenda. My first thought on this is it sounded like the person writing it was appreciative. But at the same time felt it was because of the child that they did this. And I don't know if it was a good thing or not. I don't know. I kind of got some sense that they were kind of like put on by this, they didn't like that because it was -- because it was the child that triggered this. That's the way I perceived reading this.

I just want to share another example that I had personally very similar to this.

So when my girls, they were mainstreamed. And in kindergarten again we had requested CART. And it was later that year or it was before Summer Break the principal put on -- they sent home to everybody that during the summer shut your sound off on the TV and turn on the CART because that will encourage your child to read. And I thought that was really cool. Because he didn't target the Deaf and hard-of-hearing kids. He was targeting just to encourage everyone to read. So I thought that was really cool.

Yeah. And it's the same thing when you were talking about story -- setting up that example. Like at the beginning of every year, every school year, the Deaf and hard-of-hearing teacher and then eventually the girls, they would tell their own story to everyone. Get it out in the opening right at the beginning so everybody knew why they had technology, why they used whatever. It was crazy because during elementary school everyone wanted to be in charge of my girls' FM systems because they didn't want to to go to the teacher and pass it around that's a really cool thing if you get it out in the open right away that just eliminates any questions down the road.

>> Betty here, thank you for your comment, Brenda. Yeah.

.

>> I kind of got that, too, but one of the things that I think is cool that we have in our world today is more inclusive like children's books and things like that. As an educational audiologist I try to find books whether it's ASL or BAHA or cochlear implant however they communicate. And when they see themselves in that book, the child does, it's just like this light bulb and they can't wait to share with other people I think if they can find a way to share differences is just an amazing way to just kind of be inclusive, too.

>> Betty here again. Thank you for that reminder.

I was also going to say to you Brenda this is the dad's quote -- actually they were both comments by the dad in this family and he actually appreciated genuinely this gesture, he thought it was great.

When he responded to the uncle who was showing pity towards having a Deaf child, he was like, no, in fact look at this example of what the school did to show inclusion. To our child. It was a simple gesture.

Prior to this the dad had also mentioned that their speech therapist was not in support of them signing as a family. So that was another reason that was like the school -- maybe they weren't using sign but they were at least making an effort to show what was the word that I want to use? I guess to make sign at least more visible. To the other students. So they weren't like completely dumbfounded by it.

But exposure to be more inclusive. So yes, right, like having a book like you mentioned with the Deaf or hard-of-hearing character would be another great idea in terms of inclusion.

Are there other comments about this quote?

Okay. How does time go by so quickly, that's what I want to know.

Okay. So the third and fourth passages I'll just summarize quickly.

The first one was a quote from the dad. The fourth and final was a quote from the mom.

It was interesting the dad happened to have grown up near a residential School for the Deaf and he thought that's how they do things, they separate these kids from the community. Mom happened to have had a peer who was in her peer group who happened to be Deaf and use ASL. And she had learned a little bit of sign as a result of having that friend and she felt like this is no big deal. There's really not anything different our child would go to school and do the same thing my friend did so it was very interesting their different experiences and their perceptions they got married yet they had very different backgrounds and perceptions. When they came together and ended up having a Deaf child, they both agreed that they wanted bimodal, bilingual communication for their child.

They felt like it was important for their child to be included in the community and also if possible to be included in the hearing community, as well, as much as they were interested in.

So it was very interesting to have come from such different experiences.

To have brought those to their parenting.

And the reason I brought up these particular quotes is that the parents often have very different experiences prior to -- prior to having a Deaf child.

And the goal is of course they want what's best for their child.

And sometimes they don't know what options exist.

These two parents did know about the Deaf Community. They knew about the prospect of using sign language or being in a mainstream environment or what have you. And they knew to advocate for the opportunities that they wanted to pursue.

So I think that's an important thing to reckon their behalf.

Is that many families that we work with do not know at all. They have no context from which to draw, no experience from which to draw when they are making these selections or choices.

So hopefully we can you know -- you can have more thoughts about this. But this is just some background. And we sort of have to move on before we end up running out of time.

Many of these are barriers that families mentioned directly in my interviews with them.

One example from another family is their child was not identified until the age of 21 months.

So there's a barrier right there.

One family was told repeatedly, oh, it's probably just fluid in their ear. And so it prolonged identification.

And that family didn't start processing what it might mean and look like, they sort of held off in waiting to see who their child was going to be or become as a result.

I want to say of all the five families that I interviewed, I believe one family -- I believe one family had a Deaf professional involved in their intervention.

Two of the families had an early intervention provider who was trained to work with Deaf or hard-of-hearing children.

One of them happened to be a Deaf professional. The other three didn't have any provider to speak of, they were clueless about what it means to be -- what it means to be Deaf.

And that's crucial to recognize.

Because that means that they were just getting whatever services became available to them. Or not available.

So societal barriers we're familiar with.

Some parents will say, you know, someone told me that if my child wears a hearing aid, then Deaf people will think I robbed them of their Deaf identity. And it's like oh, my goodness, how is that helpful? Just that framing.

A number of things that we could say create barriers in our work, in our interactions.

So I would like to begin doing some self-reflection, focusing on ourselves, the last category here.

And of course we're trying to improve you know societal barriers. And all of these are examples of barriers.

But where does my experience come in?

We typically focus more on screening, diagnosis, early intervention. You know, research.

We heavily focus upon those areas of influence but what about the other end of the continuum those get less of our attention, societal barriers, and the barriers that I create.

I don't know if that's the same for you.

And that's really my goal with today. Is to try to figure out how to improve the barriers to which we participate in creating and dismantling those barriers as a result of our awareness.

I think the whole point of this quote is that our beliefs as professionals are passed along to families which are subsequently passed along to their children.

And so if we believe that a Deaf person's life is going to be unfulfilled in some way, we might -- we will unintentionally pass that bias along to families. We'll take that in, internalize that. And pass it along to their children.

And I mention this because you may or may not feel the same.

But my children identifying as transgender I had to realize when my oldest came out, it really upset me.

Because a few years prior my friend, who is a mental health therapist, you know, we were just having conversation.

Just talking about the issue, the concept, of being transgender.

It hadn't applied to me on a personal level as of yet.

We were just having a chat. And she happened to mention that I'm going to quote her, in my experience, it seems like people who are transgender are transgender because they didn't feel loved in their biological gender. Their birth gender. And then when my daughter came out, I immediately felt that viscerally. That maybe I had never loved her enough in her biological gender. That she didn't feel love from me in her biological gender. Because of my friend's comment.

And so who knew that I was going to experience that firsthand?

And that's why I say what we say, we don't know when that's going to make a real impact on a person at some point down the road. We have no way of predicting what they may experience. And that's why I feel like it's so critical that we really self-reflect on our own beliefs.

Because we will comment based upon our belief systems.

And changing our belief systems is difficult.

It's not an easy prospect.

And -- well, I'll leave it at that.

I want to give you all some grace. Oh, time check.

Okay. It's 3:30. Thank you.

I thought you were saying I have 3 minutes left.

Okay. It's 3:30. Thank you.

Let me think for a moment. I lost my train of thought.

I guess it doesn't matter.

Oh, it's back.

I want you to give yourself grace.

If there are parts of these concepts that we're discussing today that are hard for you, that's fine.

It's important to recognize that none of us intentionally want to do harm, intentionally do harm.

We need to analyze what we say and what we believe so that we can avoid people feeling insulted or any harm that we might cause.

Because we don't want to hurt people, right?

We, again, we believe the best for every Deaf and hard-of-hearing child we work with. We all cross our fingers and hope for the best.

So I like this quote because it says openness to bilingual exposure. It doesn't mean that they have to be. And I think that's important, as well.

I think it's important to respect different ways in seeing opportunities author possibilities for the future.

>> So this is funny, I bumped into a comment this morning and mentioned to them that I had a Deaf gay moment this morning because my hotel neighbors above me were having sex very loudly and I was like oh, my God.

.

(Chuckles).

>> I was like I got my headphones, turned on the noise cancellation, turned the volume up on my music, I was like oh, my gosh, this is so loud.

And it reminded me that there was one time that my family was staying at a hotel and our neighbors were having sex in the other room.

And our dog was howling in unison.

(Chuckles).

.

>> So . . .

So I think okay there's definitely a benefit there. It's funny, it's a funny benefit. But it's true.

And you mentioned earlier about different technologies, too, because of Deaf experience that come up. And how they benefit other people, text and CART and cochlear implants. And how not only the Deaf and hard-of-hearing community will benefit but also it's a very diverse experience.

I think this is honestly more of the same. But I add this quote because I really appreciate the cultural and political exchange here.

Because sometimes we don't recognize that.

Let's be honest.

And we live in a capitalist society.

Money and what you earn is important in this society.

And we will fund things that typically get a Return on Investment.

Right

So that's something to recognize, as well.

Okay. This part is for you to be involved.

This is your homework.

And I want you to take time to really delve into yourself.

Look at your program's website, what it says, is it inclusive, does it create barriers, do you have videos that don't have captioning? You know the barriers that can exist.

Really analyze your program. And what you can do.

And I always feel like conferences are a waste if I can't bring something tangible home to improve upon. So this is your homework.

I love this quote, I just simply love it.

I love it says who we are. Who we are.

Not just what we think. Who we are as a collective. What type of relationship we want to create with the families that we work with, with the Deaf and hard-of-hearing adults that are in our lives.

Anyone who is involved in EHDI. The things that we support, how we advocate, whatever we do, creates who we are.

And I am becoming more of myself.

I hope you felt the opportunity here to become yourself a little bit more. And if something felt uncomfortable today, if you have any questions, please let me know.

I emailed everyone who registered before this session. But I would love to continue this discussion.

Thank you for being willing to learn this afternoon.

I know it requires a lot of vulnerability. Thank you.

That's it. And the QR code is my dissertation if you're curious in reading it. It's only 100 pages so it's not that long of a dissertation. But the family stories are beautiful.

And I have them in separate sections so you can reach each family if you want to read their stories, it's really enjoyable reading, if I do say so myself.

.

>> This is Brenda, I just want to also remind all of you to go onto your app and fill out the survey for this session, as well.

So thank you again, Betty, I enjoyed it. And I appreciated all of your comments, too.

So one other thing I wanted to share is one thing that in Minnesota what we are working on is -- and we're having a session on Tuesday morning from 9:40 to 10:40 but how we as Parent Guides can work with the families and let them know that they have access to Deaf and hard-of-hearing guides but also Deaf Mentors because we don't have Deaf Mentors as part of our Hands & Voices program but we work together in supporting the families.

So we just have been seeing a lot of success in that, you know, how we can work together and I've heard, you know, other states and other situations where again these different cultures, they are fighting each other. It's like don't fight, let's work together, we can all support the families.

So yeah.

>> It creates more barriers.

Don't fight, collaborate. Provide more opportunities, more access for everyone.

Thank you.

If anyone wants to make a comment, feel free to do so. But I didn't want you to feel like you had to stay if you want to go ahead and take off for the afternoon.

>> Yeah, out of cureity do you have any plans to do anything with the results of the dissertation?

Are you going to follow up with more research or what are future plans? Because I think this is the type of content that is important. But I do think it requires further analysis.

>> I agree.

I plan to publish something from the dissertation. I haven't as of yet decided which part there are many different things that I can glean from this. And in fact there are three other presentations that I have from this dissertation so I have to focus on before I wrote but I will.

And for this project we'll be working with SLP as an extension. Who is a postdoc. And then we'll also include Thomas Forges (phonetic) and we're hoping to do a study with the professionals. And their structure of Deafness.

So we're going to think about including SLPs, audiologists, early intervention providers. And one more. Oh, doctors.

So we're hoping to include them in the same type of study and then survey their beliefs about Deafness.

>> I think it's important to think about how to integrate Black and Brown professionals, too, into your work. But I think this is amazing.

>> That's an important piece.

We were planning to do that, we're not sure about the methodology of how, but we're going to include that in our research for sure.

>> If you're interested at some point, perhaps we could set up a videoconference to chat. Where are you now?

>> Yes, please, Connecticut.

>> Connecticut, okay. So we can set up a -- you know, a video chat or we can chat here even at the conference and talk about some possible ways to support that or advocate for that work.

>> Please. I hope you got my email. Because I emailed everyone who registered. So you should have my contact.

>> I'll take a picture of your contact here.

>> Perfect.

Any other questions or comments?

Thank you for coming.

>> I miss working with you, I have to say.

>> I know, I miss working with you, too.

>> Remember my colored pens, please leave them here.