REALTIME FILE

EHDI ANNUAL MEETING

INTERNATIONAL A

DEAF STUDENTS WITH DISABILITIES

WHY DEAF EDUCATION MATTERS

MONDAY, MARCH 4, 2019

2:15 P.M. CST

CART CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

www.captionfamily.com

\* \* \* \*

Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility. CART captioning and this realtime file may not be a totally verbatim record of the proceedings.

\* \* \* \*

>> MODERATOR: Hello, everyone! I am Anita and I will be your room monitor for this session. Now that you're here I'm going to pass around a survey sheet. I'm very excited that you're here. You're making me super excited to have you all here. I'm going to hand these out now, okay?

(Pause.)

>> MODERATOR:

>> JULIE REMS-SMARIO: We have a long table with a barrier between us, strange logistics. We moved some chairs.

But then we need to a place to put our papers. Are you guys okay with the way this is set up?

All right.

I'll begin. My name is Julie Rems-Smario. I work for the California Department of Education.

I am in the deaf and hard of hearing unit, mostly I am looking in the 0 to 5 age group.

I also do K-12 but really my focus is birth to 5. I'm here with the state EHDI coordinator for California, but in California I'm also the deaf unit program supervisor or support person. Also advocate.

You guys know what I do. That's what is most important. I also serve on the DPAC, which is the Deaf Plus Adult-Centered Planning. Deaf children with disabilities, I think you guys say DWD, which is deaf with disabilities. We'll go with that.

Oh, the mic guy!

Sorry, we may or may not need that. Is it working?

>> I'll take it. Thank you.

>> JULIE REMS-SMARIO: That was another awkward moment for you.

(Chuckles.)

>> JULIE REMS-SMARIO: So deaf with disabilities. So we are talking about students who graduated from a program and then where do they go? Where are they transitioning to? Are they staying home? Often times they are in a residence with all hearing people. They may or may not be seeing Deaf community members.

So the idea is that we have central locations where deaf with other disabilities can come. They can take field trips, participate in activities, sports teams even. Then they go back to their group home in the evenings. This is Monday through Friday program. And we see real gains in their social interactions with others and their interpersonal communication.

That's enough of an introduction, but we are talking about deaf children with disabilities.

Okay?

>> RACHEL FRIEDMAN NARR: Hello, everyone. My name is Rachel Friedman Narr. And I'm from the California State University at Northridge. CSUN as we know it.

I'm a full-time professor in the deaf education program. I teach one course related to deaf students with disabilities. And I have a whole gamut of other courses I teach, but this course is very relevant in today's topic.

My other job in addition to my full-time job is in regards to family project and parent links. I have met so many wonderful parents with these beautiful children. And often I meet families who have babies with additional disabilities.

My background is that I was a speech language pathologist. Then I fell into the field of deaf education. I've worked with many people who have disabilities. I've worked with families who are hearing parents with deaf children with disabilities. There's a real systematic gap there for services and programs to support those families, especially older students. So that brings us to the discussion about this age group of 0 to 5. And toddlers. We are not here to discuss specific strategies, but more of a macro view of the system.

What is leading to the current reality? And what do we need to be focused on in the future? So that's what we will be focusing on today.

How about 0 to 5, how many of you guys here work with the 0 to 5 age group? And these of deaf children with disabilities? Okay.

I know that there are particular challenges that these families face. Some of them are problems in the system. We have some examples to share with you.

So here is the thing. I am generally the person people ask for technological help, but today it's not happening.

Yay!

We have a tech assistant who saved the day.

It may be that you have a Cassie in your life. You might have met a baby just like her. You might have your own Cassie in your family.

Who are the parents in the room? Parents, lots of parents! Look at you.

Okay, great.

Really. She's talked about children just like Cassie. There are lots of them.

Deaf, yes, but they have some other special need or disability that we've talked about. We talk about deaf plus sometimes or deaf with disabilities. Deaf with special needs. Ah, whatever terminology you like.

Sometimes just deaf, deaf-blind, deaf with. And I've noticed that within the Deaf community it tends to be deaf or deaf-blind or deaf with a disability. They seem to be the three breakdowns.

Parents tend to say deaf plus. As for us, we honor whichever terminology you choose and we honor the transition of language as it grows and evolves. It is an empowering way to call or label or name our children and our children groups.

Really, our point in this is Cassie. What is the nature of her early intervention? What is it going to look like? Deaf hard of hearing services? Will they be needed? She's a baby. She has services for students with developmental delays. Both kind of services? That's where we find a lot of time people will focus on one or the other. People don't, one group won't have the expertise that the other has. What do we do?

I have an example. I've seen a lot and I'm sure you have too. I'm preaching to the choir.

You have a deaf child but the team says this is a child but the primary disability is XYZ, the primary disability is autism or Down's syndrome or cognitive disabilities. But where is the language services when it comes like that? When you change that focus to a primary disability? We'll talk more about that, but I wanted to show you after we start with this Cassie example, I want to show you a few examples of other things and what they might look like to you.

Let's take a look at the screen now.

Our topic: Why Deaf Education Matters. The system. You have to navigate your way through a confusing system. Parents have to figure it out.

I want to let you know it is very simple.

>> Well --

(Laughter.)

>> JULIE REMS-SMARIO: It should be simple! Am I right? It should be simple! That's why we are taking this macro perspective and looking at what should be and what is possible if and when we can take that bird's eye view. Because when you are in it, it is not simple. It is like holding this jumbled roadmap.

>> RACHEL FRIEDMAN NARR: Okay. Take a look at this. Read the screen.

Now, we put all together the research we've looked at. For school age children, we tend to assume that about 40 percent of the children, these are deaf children, have another disability, an additional disability. Which is interesting. What kind of disabilities? Hmm, that's harder to know.

What is interesting, we recently found -- maybe you would like to explain.

>> JULIE REMS-SMARIO: Yeah, I want to tell them. California was the first state to pass the LEAD-K law. And this gives us access to data for the 0-5 age bracket, including children with disabilities 0-5, looking mostly at children who have been assessed and generally the highest percentage happens in the 1 to 2, and 26 percent of those assessed have a disability.

When you take a closer look it breaks down to about 13 percent out of, I would say, 700 -- I can't remember. It's on the next slide. The exact stats we are going to look at. But when it's scene percent, those deaf children who -- 16 percent, those deaf children who have disabilities when you look at the numbers it is not exactly accurate, it is misleading because of the multiple disability category. We start identifying those disabilities later or other disabilities may manifest later and be identified later.

So what we know is that at a young age, it's 16 percent. But the number can only grow from there. Does that make sense?

>> RACHEL FRIEDMAN NARR: And what does this mean, an additional disability? That is interesting. When you look at the data for autism, okay, intellectual disabilities, cognitive disorders. Teachers often put down atresia or microtia, Wardenberg's syndrome. They will put that down. Meaning they checked off that they have another disability. Hmm ...

So that gets very, very confusing, the data. They don't really describe what that disability label is supposed to mean. That 16 percent number? Or that 40 percent number? It really means an intellectual disability. Does it really mean an intellectual disability only? I don't know.

>> JULIE REMS-SMARIO: And as she just said in the 0 to 5 age group, we haven't yet identified or labeled all of those. So that number seems much smaller. Hmm, 26 percent! Woo, that's interesting.

By school age, that number seems to have really jumped.

>> RACHEL FRIEDMAN NARR: It's true. We'll try to figure it out.

>> JULIE REMS-SMARIO: So this issue is where labels, where it becomes important about labeling primary disability. The young 0 to 3, developmental delay label, that's okay. That hides the fact of the deafness.

So that becomes more complicated.

>> RACHEL FRIEDMAN NARR: And I'll give an example of what she's describing. In the State of California and perhaps in your home states as well, if you have a child that has been identified with a disability, let's say the primary listing of those disabilities is not deafness. Let's say that they put Down's syndrome as the primary disability and deafness as secondary or tertiary. They may be placed in services based on that primary which may not serve the child well. They may end up in placement where the services they have needs for are totally being missed. That's where language acquisition opportunities start to become a problem. That's where the deaf plus or the deaf with disabilities, people are serving the child and missing those additional service needs.

>> JULIE REMS-SMARIO: Where are these children going to go? Do they go to where the primary listing is? Or do they go where the primary needs are? Of all the years we have been looking we have not solved this problem. It is the same challenge it has always been. Can you imagine the pain, grieving, and the additional pain and grieving that the parents go through as they see the child is not progressing.

>> RACHEL FRIEDMAN NARR: And the child's pain also. It's terrible.

>> JULIE REMS-SMARIO: You know, I was telling Rachel. She and I have worked together to come up with this great scheme and we came up with additional ideas and tried to poke them in there. When it comes to deaf education, intersectionality. You know, people will say to me: Are you deaf first or a woman first?

(Laughter.)

>> JULIE REMS-SMARIO: Who are you? I can't separate those two. I'm both. Am I a mother first or am I a woman first? I'm both. When does one go before the next? Same with children. Are you deaf first or have Down's syndrome first? Well, they have both and deal with both. This leads to the question of intersectionality and the multiple layers of, let's call them possibilities. That will apply to every part of their life and their future. It is not either/or. It is both. It is an identity. It is complicated.

>> RACHEL FRIEDMAN NARR: I would like to ask all of you, do you say a primary disability issue in California, we have rules and regs, primary disability, IDEA law says you can't place outside of the disability category. But in practice, ha-ha, it doesn't always happen that way.

Many times if a student has an intellectual disability, they get placed with students with other intellectual disabilities, not with students who are deaf and hard of hearing. Does anybody think that's a problem for deaf children with intellectual disabilities?

You can see, you've met those people. At 11 years old that child who is deaf, who is in a classroom with hearing kids all around them, that has a intellectual disabilities, yes, but no peers who are deaf, no communication peers who sign. She is not hearing. She may not be using hearing aids or cochlear implants. Hmm, is that placement appropriate? It's problematic.

>> JULIE REMS-SMARIO: So I've already explained that I am involved with the DPAC. You know, we have young people up to senior adults with disabilities of all types and sorts. And I can tell at a glance who had language services as a youngster and who did not. It couldn't be more blatant. These adults who had language services as youngsters are approachable, they are affectionate. They may joke or tease. They have the ability to be interpersonal and social with their peers. They may volunteer, voluntarily interact with others.

Then you take a look at those who did not receive language supports as a child. They are withdrawn. They may not join the group. They may literally sit in a corner. So this is why it is critical for all deaf children who have disabilities to receive services for all of their disabilities and diagnoses.

>> RACHEL FRIEDMAN NARR: Okay. We have discussed some of the barriers. Identifying disabilities. You know, it depends on the lens we look at it through. What is the perception? If nobody is there with a deaf perspective in that diagnostic group, it is much easier to miss things. You know, what are the signs in that baby or that very young child? What do they need to be able to -- what are the things we need to look for to make sure that that child is given an opportunity to acquire language. It is easy to miss it if you are not looking at it through the deaf lens.

That is one barrier and our early intervention system is full of auditory, a lot of people look through that auditory lens. And that becomes a barrier.

>> JULIE REMS-SMARIO: I would add, about that lens -- well, let me back up. My daughter is now in college. She's studying to become for children with autism and also other disabilities such as Down's syndrome. She is motivated. She's passionate. She's excited. She's the best advocate and friend for her students. We need more professionals and teachers and service professionals like this. There are so many schools that have a so-so teacher who a parent might say I don't want that person as a teacher.

But the worst teachers winds up with students who have additional disabilities. And that cannot be the way. We need the most passionate teachers with the most credentials and study, the most training to serve our multiple, students with multiple disabilities.

>> RACHEL FRIEDMAN NARR: Many times the child looks like they might have intellectual disabilities, but really it is a language issue. It is language deprivation issue. Nobody in their environment is feeding them that language exposure, giving them that exposure.

So it really permeates and perpetuates the problem. We've already mentioned there are not many professionals in deaf education or special ed who have all of the expertise and competencies necessary. So we need much more layering of services, much more of a collaborative approach would be healthier so we can account for everything within the intersectional relationships.

It's very interesting. You know, we are talking about why deaf education matters. You look at children at a young age or look at the home services, 0-3. Kid seems to be doing well, services are personal, more one-on-one. The child transitions into school. What happens now?

Is the deaf school discussed as an option? Sometimes Deaf school is not discussed for a child with additional disabilities. You know, sometimes deaf and hard of hearing services aren't discussed. They may be placed in another school. Is there a deaf and hard of hearing in a different kind of special school, if that's the option?

How can we maximize the student? Maybe options -- maybe the class has ten students and six of them have disability diagnoses, and the teacher is already has first, second, and third graders in the room.

>> JULIE REMS-SMARIO: All mixed together, yeah.

>> RACHEL FRIEDMAN NARR: You know? Is that your experience? Seeing those kind of classrooms?

The teacher is a little overwhelmed. What do I do now?

You know, it builds. It is a cumulative problem.

And the point is that for a Deaf student with additional disabilities, the same time they are isolated. They are, that's segregation. We don't want that. We don't want them segregated so what do we do?

You guys figure it out. What do we do? We all have to together.

>> JULIE REMS-SMARIO: I'll add another challenge. The movement of total inclusion making regular education or general education leading to that mainstream educational tore mat. We need a critical mass for our deaf children, particularly those with additional disabilities. They need to have peers and interactions and social opportunities.

>> RACHEL FRIEDMAN NARR: You've solved everything then, if you do that, critical mass.

>> JULIE REMS-SMARIO: No. It's just frustrating. It's a frustrating solution even.

I wish I brought my magic wand.

>> RACHEL FRIEDMAN NARR: You may have heard about some families who understood -- I work with many families. The baby was ill in the nick U. There are other health related factors that affect the child. We get it. Sometimes other disabilities or other issues present that trump the deaf part for awhile. However, we've got to wait. Because this is related to language exposure and development. Everything relates to language and brain development. You know? So even though yes, this obvious health concern needs to be attended to. However, at the same time you can't possibly trump or over shadow the deafness. This baby still needs language exposure. So that's where we have to marry the two.

>> JULIE REMS-SMARIO: So there now is a lot of talk about language and cognitive development in the 0-5 age bracket. Lots of talk about that with hearing children, about maximizing opportunities for language acquisition through play groups and book exposure, literacy exposure.

What about deaf children? Why are we making exceptions to those conversations? It applies to deaf children and it applies to deaf children with additional disabilities. They need to have those opportunities for cognitive development, for brain development. Have you all seen the Twitter account, I think it's a Language First. I think it's a woman who is a speech language pathologist. She made a comment and this might be too small for you to read. I'll read it: Language First Twitter and it says "Deaf children don't defy everything we know about language development."

So basically it's everything that I have been saying, right? There's all this talk about brain development and it is true. That's why we wanted to include this.

Add deaf children to this Twitter feed, to this Twitter comment!

>> RACHEL FRIEDMAN NARR: We don't want to complicate their language development any more by removing language services and exposure. And there we have it. The Deaf community, deaf children with disabilities are part of the Deaf community. As I said before, deaf, deaf-blind and -- oh, well, someone said hard of hearing, I recognize that is also an identity. But deaf with additional disabilities.

We are all part of those intersectional types of identities and we are all part of the community. I would say that all of our communities are guilty of ableism. We struggle against ableism. Those presumptions because they build barriers. They put barriers on this child, this Deaf child who has an additional disability.

Audism, you know? Or audism, we have to look at our audistic and ableistic language and views as we look at others and build barriers between ourselves and them.

>> JULIE REMS-SMARIO: So we focus on the meat of why deaf education is important, in this slide. With young babies, the family obviously -- the baby hasn't created and identity as a Deaf person, not yet. That identity might be an intersectional one eventually as they go through their journey. It's a fluid journey as they experience life. That's great.

What is important for us in the field, the professionals and the parents, to view that child as a Deaf child first. Meaning deaf, deaf-blind, hard of hearing, all of that together. I'm going to use the single word deaf to represent all of that.

Celebrating all of these identities. We have neuro diversity. We have the ability to have deaf members of our community with all sorts of backgrounds and abilities. I have some training as an artist.

>> RACHEL FRIEDMAN NARR: You're not so much an artist.

(Chuckles.)

>> JULIE REMS-SMARIO: That's great. She's great at editing me, though! She's great at catching grammar errors. I always go to her. We depend upon one another and draw strength from one another, celebrating our different schools and celebrating neuro diversity within our community.

>> RACHEL FRIEDMAN NARR: Who are we talking about? Family. So this is deaf plus young adults who just finished school, the K-12 setting. Now they are having their daily activity time in the afternoon. Look how happy they are. They get up in the morning and have something exciting to look forward to with their community activities. This is personal growth. This is independent living skills. This is interpersonal skills.

This is what our community should look like as a whole.

>> JULIE REMS-SMARIO: And this is DPAC by the way, run by a DPAC Executive Director who is the aunt of a deaf plus child. We don't really call them teachers. Really they function more as a support person and support the micro-communities and they go on field trips and they are in the community. Everyone there is deaf. So there's constant language and communication access.

>> RACHEL FRIEDMAN NARR: These could be your babies! Once they're grown up. Here they are, right?

Two years ago -- I have a quick story. Two years ago I was socializing with some parents who were telling me: My daughter, she was learning to sign. The mom was learning to sign. I said oh, is your daughter in a deaf program, mainstream school or what? She said no, she's in a program for students with multiple disabilities. I looked at her: Hmm, with hearing children? She said oh, yes. This child is 5. The little girl is 5.

I said so your child is deaf, correct? Mom said yes.

The child was, there were problems from birth, congenital issues, she has intellectual disabilities. She was immediately placed in a hearing classroom with no sign services at all. The school with the deaf program was 2 miles away and the district never said a word to the parents about it.

I was devastated. Obviously. Immediately I started chitchatting with this family, and the district as well. We tried to navigate to help the mom find a better class learning environment for her daughter. Wow! I didn't want that to happen. And that was just two years ago. Happens every year. It happens all the time.

So the word needs to spread. Really, from parents, from teachers to the administrators who are in those meetings, who are in those FSL, all those early planning meetings.

>> JULIE REMS-SMARIO: Remember, I mentioned deaf adults and having hearing allies such as Rachel. She knows what the resources are for deaf adults, how to navigate systems that are dominated by hearing people, hearing spaces. So knowing that we live in hearing worlds every day, we need some allies. We need families that are savvy with navigating through systematic barriers to receive services for their child and the ability to navigate through these complicated hearing spaces in order to find what is best for a child is called Deaf Community Cultural Wealth. This is one of the many capitals that we have. It is navigational. Knowing how systems function. It can be something simple, as simple as going into a Starbucks, making and order. You know, my daily latte! I'm a creature of habit, by the way. I never change my order. Me and my latte. They know me. I go to the same chick every day. I go in, get my latte.

She knows me. She knows what I want. She knows I don't want any sweetener or foamy stuff on top. This is what I want. This is my drink. This is my way of navigating through the Starbucks system to get to my drink.

So parents around children see me. I have grown to navigate through the hearing world. And I am a model of navigating through hearing spaces.

How many people here are familiar with this concept of deaf community cultural wealth, DCCW? Familiar concept? Great! Glad to see so many hands go up. It's more obvious in the educational systems. Those are hearing spaces most of the time, right? So you really have to take advantage of deaf people to help us. Yes? We are saying language is important, but not just language. That is not the only thing. There is more. RFA in those mainstream schools with deaf programs, one deaf child mainstreamed alone, boy, they are missing so much! That kind of capital is lost.

>> RACHEL FRIEDMAN NARR: How many of you heard the story about how some deaf child growing up in a mainstream program and has never met another deaf adult until they get to the college campus, maybe Gallaudet or NTID or RIT and they are shocked there are deaf people everywhere. They are in culture shock. Literally, culture shock.

That culture shock is usually based in: I didn't know this was a possibility for me. I didn't know they were out there. This is exposure to that capital, that wealth and bringing in those new identities as a deaf person. That knowledge is the knowledge and wisdom of our community is passed down through generations of our community. It has always been. And what I know now is not mine. It is something that came from those before me. It came to me from those in the generation before me.

So it is our goal that you can transfer that wisdom and knowledge to the families that you serve, those families with deaf children with additional disabilities particularly.

>> RACHEL FRIEDMAN NARR: And how to help those families themselves take advantage of that deaf wealth, have that community, deaf community culture with. How these families will -- the families need to meet as many varied deaf dulls as they possibly can and deaf children who are using implants, who are using hearing aids, who speak, who sign. You know, who go back and forth through our code switchers all the time. They need to meet as many people as possible as they navigate through life.

>> JULIE REMS-SMARIO: The most knowledgeable among us about working with deaf children, with additional disabilities -- do you guys have an idea? In the EHDI system it would be the parents. DPAC was developed because of a particular mother who had a deaf child with autism. A deaf mother with a deaf child with autism.

And she went to local organizations and gave us her story. We need more of this expertise.

>> RACHEL FRIEDMAN NARR: Okay. We're on six, the six capitals.

>> JULIE REMS-SMARIO: All right. It starts naturally. Language and social capitals. They come together. They coexist and they cannot be separated. They develop alongside one another. Aspirational is also important. Role models. I see someone. I identify with and I want to be like.

>> RACHEL FRIEDMAN NARR: One reason, many times I see, not so much in early intervention programs. Teachers of the deaf are great but you often see deaf teachers. Then the deaf children think my only job in life, the only thing I can do is to become a teacher. That makes me happy because, that's great, I'm a teacher. I'm fine with that.

But they need to see so many different careers and professions presented, so many different opportunities as possible. If they only see teacher, today that is not nearly enough. There are so many options.

>> JULIE REMS-SMARIO: Remember when it was a big deal, Marlee Matlin, Nyle DeMarco. There are scores of capitals out there, aspirational. They see them on trust fund, look at dancing with the stars to see who makes it to the end.

There should be scores more! How many of you know Super Deafy. Don't you love that little guy?

(Chuckles.)

>> JULIE REMS-SMARIO: You know, he is not exactly my kind of hero, but children love Super Deafy. They hug him. They tell him they love him. Aspirational capitals are so important. For living, knowing that their life has so much more to offer them. It is completely critical.

As for navigational capital, we already talked about this. I have three hearing children. You may know that. People still ask them: You have deaf parents! Do you drive them around?

(Chuckles.)

>> JULIE REMS-SMARIO: Well, no! My mom can drive herself. My dad can drive herself. That happened to me today.

>> RACHEL FRIEDMAN NARR: A family just identified with a deaf baby they will often ask: Will my child ever drive? Now, because they just don't know. That deaf baby is the first deaf person that family has ever met. So it is important for those early intervention programs to hire deaf teachers deaf role models.

I'm from southern California. We do not have many deaf early intervention teachers. We need more. It is sad.

So we need parents. We need moms and dads to see the possibilities.

>> JULIE REMS-SMARIO: The next one is resistance capital. Also imperative, especially for children in today's world, we are really having a problem with bullying. Bullying exists. And we have to teach children how to resist that bullying. Those bullying behaviors, to advocate for themselves and to ask for help. We need people to do that, especially if it is a hearing child that is oppressing a deaf child, we particularly need to give them tools, ideas, strategies to our children that resistance is imperative.

If a child is not receiving interpreting services, how do they say what they need? The child feels like there's discrimination happening but they don't know what to do about it.

Audism in the system, ableism within the system.

>> RACHEL FRIEDMAN NARR: As a hearing teacher, I know that I have a lot of knowledge, but it is not my life experience. So even though I can explain -- I can! It is not the same as a lived experience. So you need to recognize that fact.

>> JULIE REMS-SMARIO: Which is why we need allies to work with us, which is why we are giving this so much attention.

When people go to hearing people and ask questions, why not redirect them to a deaf colleague? Redirect that discussion to your deaf colleague with the lived experience, with these particular capitals that they can offer the family. Take a deaf person into the family's home when they see the deaf infants in the car seat and they put them in the house, on the floor, in the car seat. You sit on the could couch.

One time I was looking at a baby in the car seat and the mother said hang on, I'm going upstairs. I said sure thing. The baby was there in the little car seat. Facing the stairs where mom had gone, but couldn't see that I was there. I saw that the baby was stretching her little head to try to find me, to see what I was doing. The mother came back down the stairs. And I said look at your baby! Do you know what your baby is doing? She said no, what did I miss? I said your baby is trying to look at us. Look if we just adjust the car seat and that baby broke ought in the most beautiful smile. She said it never even occurred to me. That visual way of living was automatic for that baby.

And I felt like in that moment I needed to advocate for the baby. It was not the mother's fault. I had to step in. The mother wasn't resistant at all, but I had to explain to her in soft and compassionate terms. Look at your child's eyes! Look at your baby's face.

She saw what happened to her child's face. After that she became very cognizant of where she was seating her child, where she was placing her baby in the car seat.

Resistance capital, aspirational capital. Look at me. That's part of self-advocacy, right?

Can you look at me, please? We can start there with that small little step. That's one action that can teach so much wisdom.

And last but not least is linguistic capitals. It cannot be separate the from all of the things on this list. They all are interwoven. You cannot separate them.

>> RACHEL FRIEDMAN NARR: I encourage you to study more, collect more information about DCCW. Take it back to your districts. Take it back to your programs and the reason why deaf education is important for all deaf babies.

All deaf children.

>> All right. I would like to ask for five participants to look at this linguistic capital and talk about these skills with language and how we interact.

For example, let me do this right here. Is it appropriate for me to do this? You know, hearing people come up to one another and Whisper in each other's ears, right?

So teaching how we want to stay, you know, 3 feet-ish from our communication partners is something that we need to model to parents. To the children too, but there has to be a certain amount of distance for people to communicate. That's part of our communication skills and training.

>> RACHEL FRIEDMAN NARR: Can you think of others that are related to how we teach, related to language?

What about teaching children how to use an interpreter? I make up situations that they might face and the interpreter standing in front of the teacher. We are positioned, it's a problem I've noticed where the interpreter moves to the wrong place.

And my students go: Oh, hey, move! Why should I move? Well, I can't see. Okay, so then the interpreter moves. You have to be nice about it, but those kind of examples. You know, you have to teach them. They need the language access.

>> JULIE REMS-SMARIO: Are there other examples?

We can look at the next capital, but thank you for that perfect example.

Deaf schools and classes with that critical mass of deaf students, meaning not one or two but enough for social interaction with many communication peers. That is linguistic capital. I always say if you've got 30 kids that are deaf, throw them all in the same room. Their language will skyrocket naturally.

Give them some language models, they are going to go crazy. They build those skills. They build that vocabulary. Vocabulary that you may or hey not have seen before.

By the time they are in high school, it's too late. They are in there doing these freshman year, they sign it the cool way, they don't sign I am a freshman, back in my day we used the old language.

Anyway, that's how language evolves. They learn it from one another. That's because of the linguistic and social capital. Our deaf children deserve that and deaf children with disabilities deserve that.

>> RACHEL FRIEDMAN NARR: This is where the incidental language occurs. When you have a group of kids together, where everyone is interacting and using the same visual language. It doesn't happen through interpreters. They take advantage of that opportunity and interact directly.

>> JULIE REMS-SMARIO: I have a disclosure. I grew up without ASL. I did. In my mainstream class that I went into as a kindergarten, probably a four-year-old kindergarten class. As I got older I had 30 to 50 deaf children in the program, in the larger program. What I call that critical mass.

I had that critical mass mostly deaf children don't have that nowadays.

So I was better off in my day than the kids today. They don't have access to that shared language. You know, they don't have the ability to have peers and social language. Something that is instinctual.

Deaf children with additional disabilities are also human. They have the same instincts.

>> RACHEL FRIEDMAN NARR: Obviously sometimes you have to start with small steps. Babies with additional disabilities maybe should start with picture learning. Maybe they start with gestures. However, all of that happens with complete access to full language exposure and models. Even though you are modifying the input, everything around that child is full of language. Doesn't matter if it's spoken language if the baby can truly access and process, you know, and use that language that they are exposed to.

If the baby -- you know that the baby already has an intellectual disability. And you are asking them to process language that is hard to hear? Hard to access auditorially? That is really putting more stress on the brain. You're going to add to that deprivation and delay.

>> JULIE REMS-SMARIO: Something is wrong.

Okay, sorry, I'm starting to lose it, y'all.

(Laughter.)

>> JULIE REMS-SMARIO: Let's talk about equity. Our educational approaches in general start with the framework of equity. Does each child have access to that framework? Instead of a one size fits all? Well, this doesn't fit them. Let's put them over here, place them over there.

What about equity? Equity means including every child. Access for all children in this building. It is not happening in this hotel.

I'm thinking of my friend who uses a scooter, a mobility device and did not have access to this hotel. This hotel is difficult for people who use mobility devices, period. This is not equitable.

Education is pretty much this hotel. My friend has been so frustrated trying to make her way around. Education should not be frustrating. Education should be rich, exciting, fun!

Successful deaf children, success for deaf children with hearing loss. This is Karen Anderson. She talks about foundational educational opportunities to communication. That is what we have to offer. So the child has the same opportunities to learn as all other children. By the way this is used by Language First. They post a lot of good stuff, you guys.

>> RACHEL FRIEDMAN NARR: So you see the problem here? I'm teasing you. Should my child learn sign language? What is the solution? Is your child deaf or hard of hearing? If that answer is yes, the child with another disability or not, doesn't matter. Deaf or hard of hearing? Yes is the answer. Fine.

Should my child learn ASL? Yes! Maybe for 9 percent, yes, same as everybody else, but it's purple. So the answer is yes. It may look different -- ASL fore all. What the ASL looks like may vary, but you just keep adding things. You may add spoken language to it. You may add amplification to it, but don't deprive them of exposure to ASL.

>> JULIE REMS-SMARIO: Oh, someone didn't get it. Blue represented the people who said yes, you should learn to sign. The purple was they said yes too, which means 100 percent is yes! All the time, every day. The point is a little bit ridiculous, but the answer is yes.

Next? Really I wanted you to be aware the DPAC organization that I mentioned was started again because of DCCW, that cultural wealth with parents of deaf children working together and making it possible.

They are all of our children. We all must work together to raise the bar for deaf children and deaf children with additional disabilities. I'm so proud of this grassroots ever effort, this big success for these children with disabilities to have this wonderful thing to be part of, to be productive, contributor to society. Even those youngsters, older adults ... you know, maybe they are who they are. But the young adults are very active, voluntarily cleaning, picking up litter, contributing to society as part of the volunteer program. It gave them such pride in themselves.

One woman in the program, I've known her from the California School for the Deaf when she was a little one. She always had a thing for my shoes. She would always come to me and say: Julie, your shoes! I would say thank you, thank you, thank you. Now, she gets new shoes and to this day she comes to me and says: Julie, check me out!

We have this special shoe connection, she and I. But there's so much language there. She has so much language because of her mother's involvement and her pushing her daughter into the community. She is one spunky little thing and it's so easy to build confidence if you start at the beginning. You know, also teaching manners and not to be too braggadocious and whack me on the shoulder with your new shoes, but exposure to language makes her who she is today and lack of exposure breaks my heart. That is why I say again, equity for all children from the get go.

>> RACHEL FRIEDMAN NARR: Sadly, that DPAC philosophy is a northern California thing. Southern California, we don't have it. Your school districts, your communities, do they have something like that? We really need to step back and look at what the needs are and what lens we are using and use a Deaf community cultural wealth lens.

>> JULIE REMS-SMARIO: I remember when -- I know that when children are very young, parents start worrying early about that child's future. I would say 25 years ago this particular parent started working towards building that program. Seventeen years ago made some progress. Finding the funding, finding and building that program. Fundraising! Every year here there is the gala as part of EHDI. That's led by the Deaf community. We come together and have a fundraiser. We have fun. We have silent automatics. We are very creative when it comes to fundraisers. I can't remember, I'm probably not the person who should say this. All I want is the wine, but you get the idea there.

(Laughter.)

>> RACHEL FRIEDMAN NARR: You're always competing for the wine.

>> JULIE REMS-SMARIO: Always!

>> RACHEL FRIEDMAN NARR: What can we all do? First, listen and learn from the deaf people with disabilities, with the adults, those adults. Ask their experiences. Get their advice. Include them. Use their experiences and their wealth.

You have to change the mind set. The baby with a disability is still a deaf baby, deaf-blind, deaf hard of hearing, they are still deaf. We need to focus on that not fighting over what trumps, which disability is primary. No, deaf is always there because that is part of the foundation. That will help with their cognitive development, no matter what.

Obviously, trained teachers, service providers, people who know, half knowledge about so much. And comfortable with all of that interaction with people who have disabilities and with deaf people.

>> JULIE REMS-SMARIO: If you would like to know more we have so many resources to offer. You might notice that the council for exceptional children, not a lot there about deaf children but there's Hands & Voices, the American Society for Deaf Children, those are organizations very knowledgeable about children with deafness and additional disabilities. There is not a lot of cultural wealth there. So baby steps.

>> RACHEL FRIEDMAN NARR: That's it. We are going to close today. Are there any questions or comments? What is your experience from the audience?

>> AUDIENCE: Okay.

>> She needs a microphone.

>> Oh, gotcha!

>> AUDIENCE: Hi. Thank you so much for including deaf-blindness in your presentation. And for your passion for inclusivity and just equity across all kids with disabilities, including deaf-blindness.

My big question is something that I have found with kids who are deaf-blind is not a resistance to inclusion from the special education perspective but from the Deaf community. I'm wondering if you have any adviser ideas for how families can advocate and how to break into the Deaf culture and find how to learn more about that. And deaf schools as well.

>> RACHEL FRIEDMAN NARR: Thank you for asking that question. Maybe they feel as if you are preaching to the hearing -- maybe we do a little bit too much preaching to the hearing community, but really we are talking to everyone, yes. The Deaf community included. Because sometimes families, individuals are a little resistant from within the Deaf community there's some resistance. I'm starting to see some shifts. Historically, yeah, you might take us on.

>> JULIE REMS-SMARIO: Society is resistant to the Deaf community, and the Deaf community is subdivided into the many flavors of deafness. It works as trickle-down oppression. If we can remove those stereotypes and predispositions.

We know we do have a deaf-blind toddler moving to the Bay area. But I'm in northern California. So what I've done to help that family, they had a child who had Usher's syndrome. So I introduced that family to a deaf-blind person who is an adult who also had Usher's syndrome who was a wealth of information and immediately started saying: You have to learn to sign because this child will absolutely be dependent upon it later in life. So the family started signing.

That deaf-blind adult that I mentioned lives in Chicago. I'm actually going to see him tonight at 6:00 o'clock! Maybe 6:30. Anyhow, if you would like to bump into him, if you have a deaf-blind child, especially a child with Usher's syndrome, I would love to introduce you to him. He's amazing, an advocate. He is coming here with no sign support system, to buddy, there is no one guiding him. He is completely on his own. I can't wait to spend time with him. So let me know!

>> RACHEL FRIEDMAN NARR: I think everyone needs to be careful. The Deaf community, everything starts with relationships. So finding a deaf person that you know, start there. Start one at a time. Individual relationships that build larger collaborations.

>> JULIE REMS-SMARIO: If you ask me about wanting to meet a person who is deaf and has, let's say, Down's syndrome, honestly I don't have anybody in my life right now but I can always ask a friend and they ask a friend and they ask a friend and we will find that person.

>> RACHEL FRIEDMAN NARR: Networking works.

>> JULIE REMS-SMARIO: That's the cultural network I mentioned.

>> AUDIENCE: Thank you, the big piece is kids with multiple disabilities including deaf-blindness more so than kids with Usher's syndrome.

>> Do you want to respond to that? Hear from the audience?

>> AUDIENCE: So I am a deaf parent of a deaf young adult with multiple disabilities including cognitive, vision loss, CP, and several other items.

But I will just tell you in South Dakota my own friends began to show some resistance because they didn't know how to approach my son. They said he was not normal. Well, east he deaf, but he's deaf plus other. He is not vanilla. He is not a vanilla deaf baby. That's what they used to say, anyway, vanilla.

Now he's un21. I would say for the last five to six years things have gotten much better for him. With social media use, the use of Facebook. He has his own Facebook page. You know, I welcome hearing parents and family and people who have people in your life, follow him because he loves showing himself doing the laundry, doing yard work. He has a lot of things that he shows the community. I think social media has really changed the stigma. He has a Facebook pain.

Like she said having a friend of a friend of a friend, introducing friends to one another. It is such a powerful way of changing stigma.

I am a Deaf community member but I completely understand what is happening. But I will say that I can report it is getting better than it was at one time in our community.

>> JULIE REMS-SMARIO: Oh, our time is up! I just got the Chicago style ... cut it! Cut it!

>> RACHEL FRIEDMAN NARR: You're done.

(Laughter.)

>> JULIE REMS-SMARIO: Thank you all so much for coming.

(The session concluded at 3:15 p.m. CST.)

(CART captioner signing off.)

\* \* \* \*

Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility. CART captioning and this realtime file may not be a totally verbatim record of the proceedings.

\* \* \* \*