>> Good afternoon!

Everyone, thank you for coming to our presentation today. We're here from Gallaudet University. My name is porna -- I'm the director for The Center for Deaf health equity. I'm also the dean of research, chief research officer at Gallaudet University. It's a pleasure to share our work with you today.

All of you may be somewhat likely aware with ACEs and the results of those, the causes of those, physical abuse, neglect, household dysfunction. ACEs are also then connected and linked to a variety of poor behavioral outcomes, poor health outcomes, early death, and individuals can experience multiple ACEs and it's linked to multiple adversarial results that comes as a result.

Starting in 2013 or 14 I started to begin to wonder, there was a lot of movement about language deprivation and I started to wonder if there's any connection between negative communication experiences that Deaf individuals experience in their upbringing. I know in research and the link to poor behavioral health outcomes and started to research that. I applied for some funding from the national Institute National Institute of Health and received that funding for a five-year study. RO1 was a five-year study funded by the NIH.

This is the first of this type of work on a national level. Over 1500 adult participants, which I'll show a breakdown of the demographics on the next slide for you to get a sense of what data we're working with before I discuss results.

We got people in our study from Puerto Rico, Hawaii, Alaska, adults primarily ages 18 to 95, a large sample size, very gender diverse, regionally diverse.

About 43% of our participants had a high school degree only.

All the participants in the study were required to be able to communicate using ASL, to be able to participate in our study. So we didn't include individuals who are actually language deprived and couldn't actually understand our survey through ASL. They were no part of our participants.

This is a brief video. There's no voice, there's no caption or signing. There's no language in the video other than what's displayed. We're going to ask the moderator to bring the lights down so we can all view the video as it's played.

Can everyone see the video with the lights on?

If that's the case, we can leave the lights on, that's fine.

This work involved collaboration with Northwest University. Their medical school contributed support in psychometric assessments. It also involved Dr. David cella. He was the father of patient reported outcome measurements. He was involved in this work as well. It was very well designed. The it involved audiologists, providers, community members, who developed questions for this study, physicians as w ell. And a great deal of community members from all over the United States helped in terms of recruiting participants to get a diverse number of representatives who might have identified as LGBTQ and just a real diverse representation. The official results has made clear that language deprivation and communication neglect are not the same things. They're related, but they're separate constructs. And each of those constructs deserves its own type of intervention and approach. And that's actually the next step.

But first we need to test what works within each construct.

You can read on the slide, these are the types of screening questions that were asked.

Antana Holmes lie back will go into how we translated this work into a survey that was distributed and monitored to help prevent ACEs. These are the types of questions we asked in our study.

Are you able to see the graphic? I didn't realize it came out so dark. I wanted to point out a concerning finding in this study. Again, recall, we included individuals who communicate and could answer the questions. We didn't include people who had severe language deprivation as of yet, but this study showed that roughly 11% of our total sample reported never or almost never being able to understand what their caregiver or parents said or what they said to them. That is a concerning finding. What's even more concerning is on the right, that roughly 40% of our participants sample experienced communication neglect. And I'm not talking about people who missed a word here and there. I'm talking about people who felt as though they were very often or almost always left out of family communication. And from that group of 40%, that is a higher predictor of being diagnosed with depression, anxiety disorder, and disease, but from a doctor to be diagnosed with those complications. For people who experience that rarely or sometimes to never, that neglect, we didn't see that connection, that Nexus between the behavioral and mental health problems. When we talk about the 11% when it comes to language deprivation, we saw a connection between those who experienced actual language deprivation and their current outcomes, specifically diabetes, high blood pressure, co morbidity. So what that means, when we talk about that 11% it impacts the cognitive processing that those individuals are able to experience.

The other than neglect is more the emotional outcomes we see that the person who's experienced - - emotional development and mental health development as well and that can be prevented.

I want to thank EHDI for the professional work that you've done to prevent language deprivation, that you continue to do in the birth to three group. We need to move that on to older children and turn our focus there to language and communication neglect that they're experiencing. We can prevent a great number of mental health outcomes by focusing on that age group. Emanuel?

>> Hello, everybody, I'm Emanuel. I'm researching at The Center for Deaf Health Equity. And I wanted to show some video testimonials from some of our participants, the d/Deaf/Hard-of-Hearing adults who were in the study. They come from diverse backgrounds. They are going to explain some of their experiences with communication access with their families, some things they wish they had experienced, some strategies that they employed to connect with their families. So this person is going to talk about their experience as a young child socializing with hearing peers.

My mother decided to mainstream me, so I was in fact put into like a daycare program. That was probably one or two years old, maybe even three. What my mom realized right away was that I was not playing with my peers. I was playing by myself but my mom realized that wasn't the best outcome. They did some research and put me into the Deaf school that was in south British Columbia.

We have got a couple of these video testimonials. This individual is going to share their experience of the communication with their family and their wish that they had had broader access so they could participate, ask questions and so forth.

>> I want to say that my parents tried their best. I understand that. But I didn't have sign language growing up and that was a real lack. Had I had access to sign language growing up with speech as well, I think that would have been the best combination. Because sign language is more organic in terms of the ability to have in-depth conversations, the ability to ask a teacher and communicate directly with a teacher about something, I didn't ever ask a question in school.

These two testimonials are shared by two individuals explaining their experience of family communication in the home and how they did or didn't have access to incidental information.

>> It was so fast, the communication in the family, that I didn't have access to it until somebody would tell me later which meant I missed the opportunity to contribute to the conversation because it was done. There's no point in getting involved.

>> I would ask them to explain it in depth and they would tell me they were busy and I should wait. At the end of the day they finally filled me in on what had gone on.

Now we have some communication strategies that families employ to make sure there was communication at home.

When they found out I was Deaf, they were prepared at the dinner table, what would happen is people would talk and somebody would interpret and explain to me what was happening. My older brother, we grew up very, very close, he's gone now, but he would always make sure that I was included and he would get my attention and he would include me. So I don't actually feel like I missed out on that much.

And the last video testimonial is a strategy employed by a d/Deaf/Hard-of-Hearing child to get people's attention to make sure they were included.

Yeah, I always at the dinner table I would bang on the table and that would get everybody's attention and they would let me know who was speaking. Everybody would do that. The rules of the house were you bang on the table, I know to look up, I know who's going to speak and we just all employed that t echnique.

>> Those testimonials that were shared, there were some similar themes that arose. Children developed ways to get information, used visual strategies to communicate with their families. And along that process the families and the child were involved in that dialogue of strategies of what might work best for them. Families could internalize their values in making those priorities and those decisions as well.

It's important to remember also that Deaf children and their families come from a variety of backgrounds and perspectives and what works best for one family in terms of communication involves a lot of factors. Developmental interventions, language planning, and values that might look different from one family to another. The goal is not to have a strategy in place that's one size fits all. We need to ask each child and each family what approach of communication they're already using so that we can support incorporating their current approaches into our interventions.

And come from both a family and child centered perspective as well as an intersectional identity lens when we make these determinations. Tawny?

>> Good afternoon, everybody, I am Tawny Holmes lie back. Deaf Studies faculty member at Gallaudet University. I also serve as language planning policy council for chief bilingual officer which is a new office on campus.

This data can be disheartening, but at the same time I think it can give us hope, because by working together we can recognize our bias, we can recognize our systemic blocks, things we do or don't have access to, and ways that we can work together to overcome some of these gaps.

So the team got together to think about what are the opportunities, the potential actions and next steps that could be taken to prevent or mitigate ACEs. We talked about having a common statewide lens around ACCEs, so the community understands it, the early intervention community, the K-12 community, even families and other professionals, so we're all speaking the same language in terms of understanding what this data is telling us around communication experiences.

Obviously, we also need more data. We need more understanding of what's happening t o d/Deaf/Hard-of-Hearing children over the l ifespan.

The data focus on adults and their experiences, their self-reported experiences looking back, and we had ages 18 to 95 respond to our survey, so we really did get multiple generations of trauma.

Not intentional. Often not at all intentional, but trauma still happens. Parents tried their best and we struggled and I tried and all of us also have family stories that we could share.

Even those with Deaf parents might have those experiences.

These are examples that we've seen across the survey. So having the ability to be more empathetic as a result of having seen this data towards my own elderly mother. We want to understand how we can ask questions to screen for those issues so that we can identify them, so that we can get the right interventions and support to the family so they can deal with the issues right now to prevent or mitigate any long-term negative health outcomes, which of course we don't want. Once we have these measurements in place, we have got to work collaboratively to support system-wide transformation. We need to do screening through the pediatrician's office, through family medical practitioners, et cetera, school has to be involved, every system has to be involved, EHDI as well, so we're all screening on a regular basis.

So once we recognize there might be an issue, then we are going to have to step in and offer services that might require more collaboration so children and family have access to language and communication experiences. There are places that don't have EHDI services or where families are not able to access them or don't access them. Why is that? I know that for some children English is working for them, but for others it isn't, so what do we do with those kids?

And I hope that working together we can clearly identify the system of care taking. If you move from another country at the ages of 8 or 9, what are the supports that we can offer to the family? Or if a child is newly identified at a slightly older age, what can we do? We have to have kind of a comprehensive system of care.

In closing, our team really, really believes that every single child deserves full language and communication access for healthy development. I think that's our final slide. We do welcome your questions at this time.

This is thanks to, while you're thinking of questions, I'll go ahead and say thanks to the entire team who developed this work, disseminating and analyzing the data.

If there are questions, please let us know which language you'll be using.

>> I learned a lot today about communication neglect and I find it very interesting. It made me think, what stops me from connecting my lung disease to communication neglect? Why had I not made that connection? Can you expand on that?

>> Thank you for your question. My team was similarly puzzled as to why lung disease was correlated, but depression and anxiety were higher related. We did find people in that group, some were smoking and they had a smoker's history. We imagined maybe it was a coping mechanism for being left out, having anxiety and depression and of course that leads to lung disease. Next question, please.

>> [Away from mic].

>> I am looking into Adverse Childhood Experiences for children who a re d/Deaf/Hard-of-Hearing using the national survey for children's health. And from my where I'm at with my research so far, there's a compounding effect, the more Adverse Childhood Experiences you have on the negative outcomes later in life. So when you did your survey around communication, did you look at those original 10 ACEs that were found by the CDC and Kaiser Permanente, like parental mental health, substance u se, a parent that's been incarcerated? I would presume if a child is d/Deaf/Hard-of-Hearing, and either has language deprivation or communication neglect and the other ACEs I was just describing, their chances of having those poor life outcomes e xpoinent Yates. Did you look at anything around those lines?

>> I do have ACEs data that we gathered on these respondents over I think 500 people have filled out an ACEs survey, had a team of psychometricians to look at those together. We found some connection, but I need to work with experts so it's not something that I could do. But looking at ACEs and ACCEs and their related effects and how to interpret them so we don't want to harm the community by promoting results that might be overly negative, but that would definitely be the next step in the research. Any other questions? $$TRANSMIT

>> So I have two questions. One, are the two questions you showed on the screen, is that the the entire screening? And two, what is the target age range? How young could you give this to a child and it be valid?

>> Thank you for your question. This is a survey for adults. So these were self-reported outcomes. We were asking them to do a retrospective look, look back at their childhood and answer those questions. What we would do next would be to create a two-question ACCE screening questionnaire that could be used in a well-being, well child kind of visit.

But I need to work with the team to appropriately develop that kind of a screening so that it is age appropriate.

This could be answered by parents, at least for some of them. But that would be -- I'm hoping, obviously after this committee with CDC support to create a screening tool and increase the state level monitoring. Let me just add to that. Can I add to that?

I think it's important to emphasize that we did not expect these results. We honestly didn't. We just went in with these questions and over 1500 respondents, how many questions totally in this full survey? Oh, I see, of course, of course. It was a total of 50 questions. So yeah, the survey had 50 questions. You can see we interviewed people, there were videos and so forth.

And this is the data trend that emerged. So from that we came up with the idea of ACCEs. We didn't actually have that idea going into the survey. We were open to what we might find in terms of health outcomes related to early language experiences and this is what the data informed us. Specifically with communication neglect, we had 8 questions that the psychometrician recommended that we have that to be valid and reliable. We got to four items that were used.

I think actually we could reduce it further, well-being checkup to just two questions. I think we might have time for one more question. I'll just survey the audience one last time.

If not, of course feel free to visit us. We have got a website at Gallaudet and we have got flyers that we can hand out that's a summary of this research. If you come up to the front, we'll happily give you those flyers. Thank you for your time and attention this afternoon and thank you to my fellow co-presenters. Thank you so much.