>> Hello welcome. This is parent support for deaf hard of hearing-plus children and our presenter today is Jami Fries.

>> Hi, everyone. Thank you so much. I usually do this presentation with Andrea Stambaugh. But having deaf and hard of hearing plus children, sometimes unexpected things come up. She's at home with her child. In true fashion we will keep moving forward. I do have time at the end if you have any questions. Please feel free. Am I disconnecting? Is that Zoom? Should I close it?

Ok, we will just go there. Ok. So, we are going to give you a little bit about some of our Deaf and Hard of Hearing-plus kids so you can get an idea of the children we are talking about. This is Axle, Andrea's son. As you can see, Axle is Deaf and Hard of Hearing-plus. We do use that term. It can be used interchangeablely. I have heard Deaf and Hard of Hearing with additional disabilities, we have heard deaf plus, we have heard Deaf and Hard of Hearing plus. That's what I will use for today's presentation. It doesn't mean anything, it's the same concept for all three.

So, we have, Andrea and I both have a special connection with our kids. Both of our children have congenital CMV. They have a whole array of different disabilities that come with this virus. And we chose this virus because it can produce a whole different set of challenges for us as parents, for our families, and for the kids.

Axle has CMV. He is profoundly deaf in both ears, bilateral Cochlear implants. He has a complete oral aversion. Completely g-tube fed. Doesn't have water or food, anything like that in his mouth. He does have optic nerve hypoplasia. His version can go in and out. A deviated septum, he has cerebral palsy. He's in a wheelchair. He has brain malformation and calcifications on his brain. Smaller head side, delay and epilepsy. His family has a lot that encompasses this child. He is a very happy boy. We just have to shift how we raise them.

This is my son, Nathan, a 34-week old preemie. Also a CMV baby. Bilateral profound neural hearing loss. Bilateral Cochlear implants. Vestibular malformation. Aprokes ya' of speech, vision loss and type one diabetes.

So what is the term Deaf and Hard of Hearing plus? 40 to 60% of the Deaf and Hard of Hearing population is estimated to have additional health challenges that can occlude things like intellectual and cognitive processing, emotional, mental health, and behavioral functioning. Learning, ADHD and ADD, down syndrome, vision loss and blindness, cerebral palsy, orthopedic involvement or other physical challenges, autism, seizures, the list can go on and on. These are just some examples.

Some of the challenges that this community particularly faces is children in this category can maybe use sometimes use sign approximations that others don't understand. So they may have the one on one aide in the school, but the rest of the teachers, friends, social environments, they can't have that same connection if they are using sign language. Communication devices are needed. So we can talk anywhere from Cochlear implants, hearing aids, Bahas, Axle uses the switch board for yes and no answers, the AEC devices. So, it's a whole other thing to have to take around with you. To be able to get that communication access going.

These kids tend to have a very hard time with changes in routines. So, if you are going to be changing their schedule, it can throw your whole day off. It can throw off communication. It's going to throw off sleep. It's going to throw off behavior. More so than your typical child. These families tend to be very home bound in the sense that they have their routine at their home and that way they can kind of pull and go with what is comfortable with that child, because once the child goes out of whack, the whole family system goes out of whack.

Stemming, so, just for example, when my son gets stressed, he is into switches. So, anything that makes a reaction. Fireplace lights, light switches, opening and closing drawers, cupboards, touching everything. So, we have to be very careful with him when we go out in public. He loves things that have colors so, the very first day of school had to be my child that pulled the emergency exit on the bus. He's also the one that tends to touch all of the lights in the classroom in new situations. So just things that we have to be very cautious with when we are out and about. Axle is very similar with this. He tends to have his seizures when he is out and about in public when he gets stressed out. So, just extra things that we, as parents, have to be aware of. And our team, so our school system, our teachers, our nurses, our aides, we have to be a very cohesive team.

Cognitive skills and physical skills that do not align. You can have the children again I'll use Axle in his wheelchair. His physical skills don't match his cognitive skills. He's very well aware of what's going on around him but physically isn't able to do the same things. It is extremely frustrating for him. And again, I can go on and on about different examples that our kids have. I think the hardest thing for us is that there's no crystal ball for the future. We don't know what's going to be going on the next day. And it can be extremely challenging, especially when we have guidelines to meet and we have these, the 1, 3, 6 model that we really want to follow. Our kids don't fit in that bubble. So being able to say ok well we aren't here. Are we going to be able to be here in three months? Probably not. And that is really crushing as a parent. But we keep pushing forward and keep realigning where we need to go to make progress.

So with Axle, some supports that have really helped him and his family, he attends a Deaf and Hard of Hearing life skills program. He does use receptive oral communication and they are doing ASL and signed English for support for him. Cognitively, he does understand that. He struggles with signing back. Expressively, he can use approximations of signs. He has a one-on-one aide. His class can be really helpful with him. They are very patient. And that's one of the amazing parts of the lifeskills program at his school, is that all of these kids just work together. He is still really little, so Andrea's very well aware that that could shift as he grows.

Cognitive ability is much higher than the physical ability. And so vocabulary using his device can be difficult. He's unable to finger, isolate or sign touch on screen and so for him to be able to use that and use the AEC device appropriately can be really hard. And he does have some vision issues so using his vision to get the words across doesn't always work either.

>>> Some things that happened with us was just continuous diagnosis. You get the official diagnosis of a hearing loss at either birth, for us it was six months old. And since then, same thing with Axle. It's every couple of months we get another diagnosis. So it is really hard. It's overwhelming. Trying to figure out what the best path for our family, not just for him, but we also have other children. So making sure that everybody in our system is supported so we can support each other. And so, that takes time. It's finding the right medical providers that will work together I can't tell you how many times I have gone to a doctor's office and my provider said my son doesn't have CMV because he doesn't fit the model. Or ask me if I was around cats when I was pregnant. It's frustrating to get the team that is knowledgeable about all of our pieces and open and willing to be able to talk it our other healthcare providers. Because we have so many different specialists on our team and they have to work together to be able to make this a successful journey.

Getting past all of the red tape. Insurance is a nightmare. I know you all know that. But when you have medical, extra medical needs, it's just a constant battle from in-network, out of network. It's expensive. It's exhausting. I'll give you an example. We just ordered my son something for his Cochlear implants. We paid the bill and just today I got another invoice from them saying we owed like another $5,000. And I'm like -- that's just not going to happen. So, it is just a lot of time on the phone. And it's not anyone's fault, but it is frustrating.

I have spent days and months and weeks fighting with insurance battles. And it is just -- it's a piece that we shouldn't have to go through to get the correct service for our children.

We already talked about stemming. But that again is a struggle. With Nathan, with his diabetes, his blood sugar changes, it causes fatigue if they are up and down. Excitement can cause blood sugar changes if he gets sick they cause blood sugar changes. It causes mood swings. It throws off his balance with his vestibular system. It's a complex system that we have particular on our toes at all times to make sure he's safe. And has a good system so that he can make progress and be successful.

So throughout our time in family support programs we found that working with Deaf and Hard of Hearing-plus families that when a child is battling other medical diagnoses at the time, sometimes that hearing loss diagnosis isn't the one that's on the front burner. Sometimes it's the one that will go on the back. And we have to be ok with that. I talk to parents all the time in my role now that are so overwhelmed with 10 to 15 different therapy appointments every single week and we tell them, take some time off. Step back. Pick one or two you want to pick on for a few months and then rotate. Because at the end of the day with the parents being so burned out, I can guarantee that child is burned out, as well. They aren't going to be having fun in therapies, they aren't going to be engaged. They are going to be exhausted and they aren't going to make progress.

Forgetting information that was information that was given to us, because it's way too much at once. A lot of acronyms and way too much medical technology. I have heard this conference a lot today that parents are feeling overwhelmed with all of the information that is given to us at once. And while I do put this bullet point in here, I also want to point out that I think that it's important to give it to us to be able to go through at our own pace. So I love when my providers leave things with me at home. Written documentation, resources to be able to go look at. So, when they aren't there, and I am mentally ready and, to go, I can go back in there and say ok now I have the time, now I have the mental capability to look at this and I can learn. It doesn't always have to be with a medical provider there in the room.

Again, having to utilize multiple pieces of medical equipment, it can seem unimaginable and financially impossible. It's just hard. I mean we have wheelchairs, feeding tubes, insulin pumps, continuous glucose monitors, Cochlear implants for both of us, we have all the extra accessories that go with it. We kind of feel like we have a child that's in kindergarten, first grade, walking around with the value of a Lamborghini on them and it's terrifying. So just, you know, keeping that in the back of our mind, as well.

And the cognitive ability of the child. It's a risk and benefit. We don't know where they are sitting cognitively and what they are understanding. I would always say continue to meet the child and the family where they are and keep pushing them, but be patient if there are setbacks.

>>> One of our programs that we do, Andrea and I both work for hands and voices. The guy by our side program. It's an amazing program to be able to meet with other families that are in similar situations. They give you unbiased information on communication models so that can be helpful if you are trying to figure out what will fit with your child at the time. We always say, you know, if it's not working it's ok, try something different. It doesn't have to be a one size fits all. You get one on one parent support and resources, trained parent guides just to call and chat, meet with you, text with you. Andrea and I both support a role in our chapters that are Deaf and Hard of Hearing-plus guides so we get the families that have additional needs and have struggles so that way we connect because it's a different journey than families that are just dealing with a hearing difference or hearing loss diagnosis.

We do help families identify their options. Tell them which options that they can pick through, giving them local resources to find supporting families. It's all about meeting the families where they are. And that's what is the most important piece. Helping them navigate the many systems and services available in their state, territory and region. It can be, again, overwhelming. There are so many loopholes, so many different services available for each different section. Working with the team of professionals, each state works a little bit differently. Early intervention and make insuring we are in contact with the early intervention team as well to make sure that family is supported not only physically but emotionally. I said Andrea and I both do the Deaf and Hard of Hearing-plus. That's a unique piece.

Social media. The good, the bad and the ugly. I will say having a child that has such a unique diagnosis is really, really hard to connect with other families that live in your area. Facebook, social media, Instagram, twitter, tiktok, wherever you want to go, they can all be amazing. But they can also be horrible.

We have so many people that want to come out and judge what parents are doing. And it's much easier to do over social media and I think we have all probably experienced that in this room at some point. And so, we have to be very cautious when what we are posting and, two, for professionals and families, we don't know where that family is sitting, what resources they have, where they live, what their income is, what their insurance is available. You know. We have, I have seen so many people going you guys just need to drive the hour. And these families are -- I don't have a car that can fit my child's wheelchair in it. How am I supposed to get them there? How am I supposed to find ASL classes when we live in a rural area that doesn't have anything for five and a half hours? We don't have Internet connection at our house. There's a lot of pieces. It all comes very easily on social media but there can be really great resources on there and really, really great support systems. Some of them will be your individual state hands and voices Facebook pages. There is a Deaf and Hard of Hearing Facebook group that is very supportive and very well monitored. So that way, everyone in the room is very well aware of the rules and we are there to support each other. There are specialized social media groups so like for example with CMV, there's a couple of CMV pages for parents so I would say if you have a child that has an additional diagnosis to look and see if there's a support group online for that specific diagnosis. There's a lot of families that do individual family stories or personal pages kind of for awareness models but also to connect with other families. And so we have seen that a lot. And that can be really helpful if you are doing things like maybe social fundraisers to help get an upgraded wheelchair or to get a specialized highchair. Upgrades for vans, so they are wheelchair accessible. I have seen a lot of our friends on social media use their personal pages that have a lot of friendships on there to be able to do those kinds of fundraisers. They do things like car washes or t-shirt sales or the bracelet sales, just simple little things but they can actually really help and it does help you make a connection and help connect and get with people who understand it from all over the world.

>>> It is hard, though, because there's a lot of misinformation on there. So you will get parents on there who come in and have been told something from a provider that may or may not be correct. So, it's really important, if you are a provider, to let families know if you are guiding them in that direction to make sure that they are bringing the information back to you so you can talk about it together. There's a lot of it out there.

You don't get the in-person connection.

Hands and voices leased a document in 2021, it's a community support for connecting families of children who are Deaf and Hard of Hearing plus. With resources and support so it's all in a really nice document. It is on the headquarters page. These slides are in our -- the slide deck on the app. So, if you go in there, you can click on that link and it will take you right to it. But it was developed by the early hearing detection interconvention parent to parent committee for families with Deaf and Hard of Hearing plus. We know that the ability it reach their potential is the heart of an issue of a journey of raising a child who is Deaf and Hard of Hearing plus. We want to make sure that these families know how, where, and why they have access to these expertise resources and information and to share the information about the benefits and the availability of connections to other families and adults who are Deaf and Hard of Hearing plus. We need the support from all around.

>> I don't like to leave you all with the struggles of raising a Deaf and Hard of Hearing child, because there are so many benefits to it. This picture was taken five EHDIs go now. I think it was five. With all of the CMV moms that come here. And we get different ones that come every single year. We are all still great friends. We talk all the time. We have each other's phone numbers. This is just such -- well I should say parents, excuse me. We do have a gentleman in the picture as well. He's not as active but his wife is very active with us over text message. It is such a great connection point. Our children give us a new purpose in life. They give us a new way to see the world. I can tell you that I see things through my son's eyes now that I would have never seen otherwise. We find the strength in our selfs that we may have never known was there. We learn how to fight, we learn how to advocate. We learn how to push until we get what we need. We have hugs, smiles, laughter. There's a lot of tears, too. But, we get a new friend in community and that support system is something that I would never, ever take away from this. So, one of my little quotes that I like to live you with is I wish I could take away my child's pain and struggles but I would not change him for the world. I am so proud of who he is and thankful every day that he continues to show me the world through his eyes. And with that -- I would like to leave you all with time for questions.

>> So as a provider of early intervention services, can you share with me the most helpful and least helpful thing that a provider has said to you?

>> I'm going to go least first. I like to leave on a positive note. The least helpful was asking why something wasn't done. Why we had not accomplished something. Why we didn't have the newest technology. We have gotten quite a bit of that. Throughout the years. We have a very good service team now that is very aware of where I stand.

I will say that the best thing that I have had, I will go back it my early intervention team that we had. In the fact that, well all of ours now but started with early intervention including my other son. I have two boys. A 10-year-old and now-7-year-old. Watching my 10-year-old come in and sit through appointments and have to sit quietly in the corner which is just not the child he is, was not only unfair to him, but it was extremely stressful to me as a mom. Because I was constantly trying to keep him quiet, which just in reality is not going to happen. So, the providers that actually came in with a plan for a family unit, included my other son, brought him in with us, whether it be audiology appointments and they would let him come back and help push the buttons on the keyboard, that made him feel so important and I didn't have to focus on him. I could focus on my other son.

Early intervention, any time they brought little presents whether it be like for Halloween or Christmas, little baggies, they always brought two. So my other son always felt included in the progress and in our journey and I don't think he's ever felt resentful, which has really helped me as a mom and our family be able to thrive with the world that we are creating in our home.

>> Not really question, but I just wanted to add that as a mom that has to go back and forth with the insurance company, what I found is you have a peer coordinator. You can filter all of the back and forth through them and you have that initial conversation with them and they go ahead and run the extra leg for you and then get back with you so that you aren't saying the same thing like five times on the same call and to talk to someone for maybe like three minutes that hasn't really answered your question or helped solve the problem. So -- just wanted to share that about care coordination through our private insurance companies.

>> Thank you. Yeah, we had one of those for a little while and then we got a new care coordinator and then a new care coordinator and it was just the same thing over and over again. So -- but they are very helpful when they are efficient.

Anybody else? We have a couple minutes but I don't want it keep you all here if you want to go walk. Since none of us have done that this week.

Ok. Well thank you so much. And I hope you all enjoy the rest of your afternoon since it's the last day of EHDI.