>> AMY: My name is Amy Keslinke. I'm a parent guide with Illinois Hands & Voices Guide By Your Side. And my presentation is called "It'S Complicated: A Parent'S Experience Supporting Her DHH Child Through a Traumatic Medical Experience." If you were here for the previous session, this is kind of perfect scheduling, because the last one was sort of the -- I want to say scientific side of the experience of trauma and how you deal with it in your practice, and this is more of our story, so you can see what some of that looks like in our situation.

So, again,my name is Amy. This is my son and I, his name is Evan. My background is education, I've talked third grade up through adult education. I'm a parent guide with Illinois Hands & Voices Guide By Your Side and also a parent facilitator with the Illinois Service Resource Center and a medical mom.

My objectives today are just to sort of give you a look at a firsthand -- well, it will be a secondhand experience, but share with you my firsthand experience of what medical trauma has looked like for my child and my family. I have a little information in there about pediatric medical trauma, but I'm definitely not a scientist in that regard, so this is coming from my personal lens.

And really just to reflect on your own practices and what this might look like with the families that you work with with what they may have experienced that you may or may not know.

So pediatric medical trauma. Early childhood is an especially vulnerable stage for medical trauma because it's a rapid time of development, something we all know in neurological systems, relationships,e motions, basically everything is developing quite a bit in this time. So up to 30% of young children, which in the situation is zero to six, experience pediatric medical traumatic stress within the first month of an illness or an injury. And between 3 and 10% of children will develop post-traumatic stress disorder as a result of a traumatic medical experience.

And then when you have a child who is deaf and hard of hearing in a traumatic medical situation, you also are looking at information deprivation trauma, which is defined as fear, hopelessness, or another negative emotional response as a result of lack of understanding or inability to access information regarding a meaningful event.

So my son Evan is no stranger to to the hospital. He was born with a congenital heart defect. He spent most of the first six months of his life in the cardiac ICU, and he had just this past summer, he had his third open heart surgery at four years old.

Most of my presentation today is going to focus on this particular past summer in which he had that open heart surgery, but he has spent probably cumulatively one of his four years of life in the hospital altogether.

So, this summer, like I said, he had an open heart surgery. This was his third. But his other -- his previous were before he turned one. We were aware of the surgery, we were kind of -- we had been waiting for it, and doing a lot of other cardiac testing to see how long we could hold it off. He has a lot of other medical needs. He uses a wheelchair, and now transitioning to a walk or. So it wasn't something as clear as, oh, this needs to be fixed, let's go fix it. It was a lot of when is the right time and a lot of checking and that.

So going into surgery in the first place, there was a lot of buildup of medical trauma. He has something called a cardiac catheterization. About every six months. And a cardiac catheterization is when you kind of hear of it with older people who have blockages in arteries, where you go in through a vein to open it up. He has a similar procedure for different reasons.

So by four, he's very aware of the difference between a regular exam room in the hospital and what a pre-op room looks like. When we go to pre-op he's pretty well aware this is not a typical appointment.

This particular picture by the way was when he had his cochlear implant. So this is further back, but I don't have very many good pre-op pictures, and he's just so darn cute, I have to include that.

So I, as a parent -- and I think one who is a strong advocate, I'm very lacking in my empowerment in asking for an interpreter. Evan mostly uses -- he's a total communication kid, but he does rely heavily on ASL, and there is some sort of something in me as a parent who feels very guilty asking for that. I have gotten -- I want to say pushback, but I don't think it's intended to be pushback from the medical community about whether or not that is necessary. So usually in his most recent surgery was when I asked for an interpreter, and I was asked why.

I said, because he uses ASL. And the experience of having an interpreter was not helpful. So there is the importance of me learning to stand up and ask for it and make sure that it's an interpreter who is -- edidn't practice being very politically correct -- who is being professional, it's part of my learning experience as well.

So the language experience is obviously difficult, especially when there's not an interpreter, but even if I do ask for a interpreter, it's definitely a challenge as well.

One thing that makes it particularly challenging with a little boy is he has a tendency to get upset and close his eyes, because he's so upset and showing how he's feeling. And when you are trying to use ASL with closed eyes, things don't go clearly.

And then just aside from communication, as a parent, it's very difficult to contain my anxiety. We all know that kids play off of their parents in almost all situations, and I really do my own work as far as containing my anxiety or the way it presents itself with an event such as this, but when taking your child to open heart surgery, there's truly no other way to describe it.

We have also had the experience of being sent home at the last minute on more than one occasion. So you also are always in that moment of what is -- what is about to happen?

The presenter before me talked about that, not knowing what is about to happen moment, and that feeling is very intense, and everything inside you is like even just talking about it, I'm feeling like... all of a sudden.

So it's hard for me to rein that in as a mom and not project it on him. So it requires a lot of focus for me as a person on containing myself, which makes it hard to interact in that talking to doctors.

So on this particular surgery, things did not go according to plan, and we were in the waiting room for about 10 hours, I believe, and people working in the hospital had started to go home. And we were starting to get very little information. And now I know that the reason for that is that things in the OR were not going well. And so a dock or tore that was not the one I expected to see came up and told me that Evan would be coming upstairs on something called ECMO. And that stands for extra corporeal membrane oxygenation. It is use when life support is needed after surgery and you're very ill in your heart and lungs need help to heal. That's the Mayo Clinic definition. There are various risks involved in this, but ECMO was in my mom brain the worst case scenario other than the obvious unspeakable worst case scenario. I having spent a large amount of time in the hospital had seen kids on ECMO and seen how things ended up. And usually I did not see things end up in a positive way.

So when I was told this, that is probably the worst moment I've had in my entire life.

[ no audio ]

Hello... testing, testing.

How was that for a cliffhanger... the worst moment I've had in my entire life... and then drop.

Welcome to the party.

So ECMO is essentially when somebody has open heart surgery they're on something called bypass. And ECMO is essentially bypass in an inpatient room. And so for eight days we were in the room with a large machine that was literally doing the work of my son's heart, and so it would be pumping the blood through the machine and out of the machine. And it's this very strange sense of what happens if the power goes out in here?

And I know the answer to that, obviously, a hospital has generators, but it's an eerie feeling of sitting in the room and knowing there is one machine that is sustaining your child's life.

Strangely, though, being in that moment, when I finally started to get the information, my stress about it started to get better.

So the more information a family has, the better. But that brings us back to the information deprivation piece. I am a hearing person, so I didn't have a communication breakdown, thankfully. I can't imagine the experience of a parent who has a language barrier, be that in communication or in different languages. So the trauma of that experience would be exponentially larger than this one.

So then what does the child perceive in this situation?

And there's not a complete definition, because I can't interview my son about it. He's nonverbal and doesn't have the vocabulary to tell me. But in my research, I found -- and from what I know -- sedation makes visual communication impossible.

So a lot of times, if you watch medical dramas, if you have never been in that sort of medical setting, they're talking to the person and duh-duh-duh-duh... and singing... and you can do all those things, but it's a strange feeling as a parent of not knowing what, if anything, is getting through.

Because when you are on ECMO, you have to be medically sedated, because if you move, you have problems. Everything has to stay connected where it's supposed to be.

So lots of sedation, lots of medication. However, you know that they are feeling or perceiving something, because nursing will take a very close look at blood pressure, heart rate, and small movements as indicators of pain. So... which is a good thing, because I don't want him to be in pain and have no one to know, but it also does make you as a parent wonder how much is he perceiving what is going on around him and how can mommy he.

So the first eight days were obviously very intense and then he did successfully come off ECMO. And then things slowly and steadily started to progress.

So waking up from something as significant as this has a lot of things to overcome.

So first there's the element of confusion. Because for him, he doesn't have the language for the communication for us to explain it to him, so he fully understands. He's on an inpatient situation where mom or dad are the only one there who is signing. I did not ask for an interpreter inpatient. I don't even know how that works still, because overall we were in the hospital for over 30 days -- no, 27 days, I believe.

I can't imagine that they would have an interpreter on call at all times. I assume it probably would have been video, and at that point, there was so much for me that it was just enough for me to keep it together in those times.

So obviously he was very confused. There's also the element of the needs of us as parents. So sometimes we have to walk away and get something to eat or go to the bathroom or get water or something, and in the hospital they do their best to help you with that, but especially in recent history, when staffing is problematic, it's very difficult as a parent to get away for a few minutes. And we do have another child, which made it all even more difficult.

Then there's element of discomfort, physical discomfort and also discomfort of not being at home. When we're sick we want to be at home in our own cozy bed and own cozy things and this is obviously feeling sick in a situation where you're not comfortable. He does use a wheelchair, and after open heart surgery it's important to be upright and be moving and that's already a challenge in the first place. So for me as a mom, my perfectionism comes through there, we need to sit up and we need to get better and get out of here. But it's not that simple.

So finally we get to a point where we are having some more true recovery, and I wanted to point out some of the things that really made that a little more possible.

So one fortunate thing about being a family who spends quite a bit of time in the hospital is you start to form relationships. And so there were some familiar faces in the hospital, and some particularly joyful nurses who would be willing to stop in his room and play peekaboo through the window. And even just that little moment when mom or dad has to step away, knowing that somebody else would be there to make him smile, it's huge for parents but also huge also for him. When a signer did show up, I was like a light in the room. We were very thankful that an SLP on the unit that he was on could sign, and after Evan figured out that guy could sign, every time he showed up at the door, his face would light up. And that was very rare. It is very rare in the hospital. In fact, I usually take it as a win if he doesn't cry when somebody shows up at the door. That used to be the sign. But now the fact that -- I'm not sure I had ever seen him smile when someone showed up that wasn't a family member. It was huge.

So I'm sure that that person did not use sign every day, but the fact that he would go for it with him made a huge difference.

And on many Children's Hospital units, there is something called Child Life, or a Child Life Specialist. And those are people who are trained in helping make the experience less traumatic for children. It's important to note less traumatic and not "not traumatic," because I'm not sure that is possible. But they are really valuable in taking the time to talk about what Evan likes and what might make Evan more comfortable rather than just dropping off some toys, which in some situations if you have ever been to the ER with a child, sometimes they'll say would you like Child Life to come down and then they come down with a coloring book and stuffed animal and you're like, thanks!

On a unit they can be more one-on-one with you, which is very valuable.

So as he starts to get more healthy, we are really grasping at normal. So thankfully in the hospital we were allowed one family visit every two weeks.

So like I said earlier, we have another child, and she was able to visit once during his stay. This was quite a hot button issue with Evan's mom on the unit, because scheduling in the hospital, we call it "hospital time," if you have ever heard of that, because it's just the way they want to do it. And so that morning -- no, the night before I was told that he was going to go have a small procedure to have like a line put in. I didn't really want him to have it in the first place, but it would have required him to be sedated, an that's when his sister was supposed to come. And I... like my anxiety went crazy, and thankfully, this was a situation where knowing people helped, because there is a doctor who is a mom, and I kind of had to like look at her and she had to see that Evan's mom is like going to lose it, and I just explained it to her that this is my other one is having a very hard time with the fact she hasn't seen her brother in a long time. I've been telling her that she gets to come see her brother. If he is sedated and asleep, this is going to cause us big problems. And in my mom heart I just wanted my babies to be together, because of scheduling that wasn't going to be able to happen. So thankfully I could advocate for that and that changed. I know many families who are not -- don't feel comfortable stepping up and saying "no," and if the doctor told him that we're going to put this line in at 12:00, then that's what they're going to do.

And so there's compounded trauma on top of that.

Sleep is difficult in a hospital in general. And play is difficult. Logistically having a child with multiple needs, getting him to be in a seated position where he could planed joy himself a not be frustrated by the way he had to sit was a challenge in itself. So this third picture is one of his -- one of the last days before we got to go home and he was finally starting to seem more like his lovely little self. Now that it's behind us, what do I want you to know? I think it's important to explain things as clearly as possible what we're doing at an appointment with the child.

So that means that I as a parent need to know exactly what we're doing.

So usually my plan is that I'm explaining to him when we get in the car, mom and Evan go to the hospital together. No pokes. No pokes. We see doctor. We talk. Then we go home.

and I and it's important for me to know because if I tell him no pokes and there are pokes, we have work to do after that to get him to trust us again.

And really we have been trying to establish heart surgery as a point. Me's in a total communication program and there is a staff member who subs who had open heart surgery, so when she's there, she's... surgery too. We are same.

And so now he started, when I change his clothes for him to point to his scar and say... he said "same" to me. No, not mama, not "same."

But that's important for him to take ownership over that experience that he's had.

A few other things to remember is that the trauma is real for both of us. And I shouldn't even have said "both of us." I should have said "all of us," because my husband, I'm sure the trauma is significant, and stereotypical men don't share it very often, so I can't speak much to his experience. And for my daughter as well.

I'm sure that you guys all know, but don't question interpret requests. Even if you're asking for how long do you need the interpreter, because as soon as I get a question, I start to doubt it. Well, does he really need an interpreter? Can we do it a little shorter? I'm causing these people so much trouble. They probably think I'm really annoying and I'm just coming in to be this mom that is going to yell about an interpreter. Just think, okay, this is all we need. And know the family's communication preferences. I kind of, in a perfect world, feel like I wouldn't have to ask for the interpreter, because a child who spent so much time in the hospital, there should be something there that shows that he communicates visually and there should be people at our disposal, but that's not the reality.

So my final thought is that we don't get over or move on from trauma. This is unfortunately an unknown quote. It was so good, I wish I could find it.

We don't get over our move on from trauma. We are forced to make space for it. We carry it. We learn to live with it. And sometimes we thrive in spite of it.

My sources are at the end of my PowerPoint if you would like to take a look at any of them.

And thank you so much for your time and letting me share my story. I might have time for one question, but I'm an open book if you want to come up and ask me at any time.

>> We have about three minutes. So one question if anybody has a question. I'll just send around the microphone.

>> AMY: Such a fun thing to talk about, I'm sure it's intimidating to ask a mom about her four-year-old's open heart surgery. I get it. You have to joke about it. Maybe that's my coping mechanism.

Thank you so much, everybody, for your time.

Oh, there is one, just at the last minute when we gave up.

>> AUDIENCE MEMBER: So kind of question, kind of just something to be going through is that when there is open heart surgery on the table or something along those lines, and then jugging any sort of hard of hearing diagnosis, prioritizing. And then as a professional in the hearing -- you know, in audiology, working with those priorities, and how have you and your family dealt with that? Have you had issues with that, where certain people want you to be somewhere at one time and you're like, this is just not a priority right now?

>> AMY: Absolutely all the time. It ebbs and flows. I was talking in a different presentation about how there was a time where I was having to pull him out of school all the time, because when a specialist calls you for an appointment, they don't say, when would be a good time, they say I've got you on the schedule for June 5th at 4:00 p.m. And you're like, great, that's after school, but rarely does it happen. Now I'm in a place where his health is more stable so I've been saying "no" to a lot of appointments and say I can't come in if it's before 4:00. And there's the whole piece of working as a family, and my husband and I don't have paid time off. So going to any appointment, even if it's audiology or whatever is our highest priority is a literally cost financially to our family because we're not making money, we're going to an appointment.

So thank you for pointing that out. Because it definitely is significant.

And also a source of trauma in itself. Because we thankfully have a good amount of resources, but it's still inciting a lot of fear about having enough money and what are we sacrificing because of that.

So, thank you.

>> Unfortunately that is all the time we have today, but I know Amy would be happy to chat after.

>> AMY: Thank you so much.

>> And remember to fill out the evaluation.