>> PRESENTER: Awesome. All right. Welcome everybody. Amy and myself are going to talk about Deaf with disabilities. We are going to talk about my daughter who has -- who has ADHD as well as Deafness and then Amy's child is a little more complex. So we are going to give you a little bit of both and how we live our lives with our kids and help them.... If I can get it to move.

>> PRESENTER: So how many children are we talking about? When we think of which I shall who are Deaf and hard of hearing, 40-50% of them are something else that they are walking with every day, that that I are dealing with every day. So it's important to understand that when a professional works with a child or a parent has a child who is Deaf or hard of hearing, there's probably, or possibly something else going on. There are over 400 syndromes that have hearing loss as a symptom of that syndrome. That's a lot and we have kids who could have multiple diagnoses going on and multiple diagnoses that could have hearing loss se a symptom so we need to keep that in mind.

Here are the most common. Waardenburg, usher, Pendred, stickler, charge, NFII, Alport. But there's many more and then you have the families that there's only 8 of us and we are one of them. It's all over the place.

The 3 most common are sensory processing disorder. ADHD and learning disabilities. So, let's talk about my daughter SAHH man that, now 21 old. Profoundly Deaf, utilizing bilateral cochlear implants, is currently a Jr. at RIT. So, I give that information because in a lot of ways that diagnoses was easier many the education system than the ADHD was.

Did a great job but the ADHD there was no one there working with her for those skills and those needs. She has struggled with depression, anxiety, isolation, she is a chronic complainer, which so is my mother, so I think it might be hereditary.

She has a really hard time finding the silver lining in anything. Um, it's all part of that ADHD. Does anybody in here have a child with ADHD? Or themselves have ADHD?

Um... yeah. It's not an easy thing to live with, and it's invisible. So it's oftentimes thought of as, well they are just a rotten person. That's not true, they are just stinking amazing. We just think differently, and I say "We" because I have it too. For her friendships, you have to earn a place in her life as a friend. So if you are not -- so if we go into a conference, like for instance Amy and I we work together, she's my friend, my daughter would not see Amy as her friend. She's not in a high enough position for her to consider that. So it's difficult to talk to her about friendships because it's not the same as what we consider typical friendships. So if you have -- who in the room is a professional? Working with kids? So if you have these can I and they do have the comorbid diagnoses, know that these things are more difficult for them. They are a little more black and white than your average kid and they do feel isolated. They do feel like why am I so different than they are? My daughter has found her tribe. I think they all have ADHD. But they -- she found them and where did she find them? Online.

Why? Because she didn't have to put herself out there, physically, to do that and it was easier for her to hide behind. When she felt that they were finally friends. So it is very debilitating because what do we teach in school. Relationships. Having those strong core relationships. We tell our kids when you go to college "Oh, these could be your lifelong friends."

My daughter can hardly get along with her roommate. You know? And the roommate is the same, I think she's ADHD too. So, these are difficult things and we have to switch our perspective when we are thinking about them and their needs, especially socially.

So she has combined type, she is hyperactive, but she's more impulsive. I can remember in almost every IEP meeting, saying she tries to steal my pencil in session. She doesn't need the pencil but it's there and she's going to see if she can take it and the professional would say "I'm right here, I'm watching you take the pencil."

I wasn't taking the pencil. She's just very impulsive. Sometimes her reactions are very impulsive, too, which doesn't help relationship, as well. Please keep in mind that ADHD is not a choice that the child is making.

They can't help how they are behaving. It's important to provide them with incentives, a sticker for a kid with ADHD goes a long way. Give extra praise and encouragement because it's few and far between that they get it. Because they are more the problem student in the class. Follow a step-by-step approach. Gray area is hard for kids with ADHD. Let them learn special deliver, not only does this give them a sense of belonging but it gives them a break from whatever they are doing in the moment. Alternate action with requests for attending. And consider adding spontaneous exercise. She did a session, our district does a Read and Run summer program. And she was falling behind in reading felt she took this for 6 weeks, they would read a paragraph, then run around the gym and come back and talk about the paragraph. She did so well that they implemented it in school. She wasn't running around in class but she was able to take something if it needed to be delivered somewhere. So it's just those little steps.

Visual distractions are really, really hard. The squirrel effect is real. Don't put them next to the window. If there's something going on out there, they're not hearing anything you have to say. Provide good listening environments, especially with kids who have some usable hearing. Um, agree on a small signal. Our 5th grade teacher, we actually um... nominated her for a golden apple and she got it. With Samantha new, she would go over and put her hand on the desk and she knew and it would let her reconnect to what she was supposed to be doing.

Enlist the parents to help. If you're struggling with the sessions or with the student, who are mom and dad. Don't sweat the small stuff, because there's going to be a lot of it. Capitalize on their sense of humor, because they are typically quite funny. It's their defense mechanism, from their body that needs to move.

And listen to what they are saying. They have a lot to say.

Don't take the easy way out with these kids. Don't do it for them. Don't let them get away with it. Make them do it, say it, if they want it. If you want it, go get it yourself. What do you want? I'm not here for you, to get that item for you. You go get it yourself. When we go to restaurants, it's the most painful experience for her to order, and I guess you're going to go hungry. She figures it out and she orders.

Make them write daily, weekly and monthly to-dos and make sure to check on them. Give them a planner as soon as they can write because they are going to need it. And most importantly, love them because they are pretty darn lovable. I'm going to pass it over to Amy to talk about Evan.

>> PRESENTER: This is my favorite little boy, Evan. He has a complicated medical history is usually what the top of his file says. Um, I could probably do it 25 minute session on all of these things so I'm just going to highlight some of them.

The biggest things is that he was born with congenital heart disease and he has had 3 open heart surgeries to date. He also has 22Q11 duplication syndrome, which if you've heard Degeorge, it's the opposite. Degeorge is a deletion, he has a duplication. When we found out we were told it could mean everything or nothing. It's just a piece of information.

He also has one cochlear implant and no amplification on the other side. And then let's see, what are some of the highlights? Something called Horner's syndrome which is why one of his eyes is much more closed than the other. He had a nerve damaged during his open heart surgery that affects some of the muscles on that side of his face. He uses oxygen at home, he's on blood thinner, he has anaphylactic food allergys and working on a walker. He attends a DHH awareness program. He participated in early intervention for -- I want to say all of his 3 years but whenever he was hospitalized he was not participated but was enrolled the whole time. He received PT, OT, social work, extra speech for AAC and nutrition. So we had a big, big team.

Um, I mentioned his total communication. He prefers to sign, we are also working on AAC, he doesn't really love it because his motor skills have made it difficult historically, but we are getting there and he receives OT, PT, speech and social work at school and also, is a signed a one-on-one paraprofessional.

Some of the struggles that we have had are um... well... he has low muscle tone. A lot of specialists are so experts in their own field that it can be hard to make people understand that you can't isolate any of the pieces. So he has low muscle tone. In -- for that reason, signing can be difficult for him to do, clearly. So, we have to approximate a lot of things. Right now working through his IEP, we are talking a lot about how many letters of the alphabet he can make his hand create. And working on getting more OT minutes, in order to be able to sign more accurately. All of the pieces resolve around each other. Because of his medical needs and the trauma associated with him, the second cochlear implant is a low priority on the list. Having a kid with multiple medical needs makes everything sort of a juggling act and sometimes hearing is the most important thing and a lot of times it's not. Um, so he may get a second cochlear implant, personally mom has had enough surgery so mom might just wait and let him decide for himself when he's old enough. But we shall see. His health can change quickly. Within day he might be fine and then he could come home, this happened last week. He was fine all day, we were in the ER by 9 p.m. pause his heart rate was elevated. He had an ear infection, and he's so used to pain, he didn't tell us or show us until his eardrum had ruptured. So he was pretty sick, but we didn't know. Lots of medical appointments, and sometimes a lot of times pulling him out of school is the only choice. I feel like the more specialized a doctor is, the fewer opportunities I have for scheduling, so a lot of times I have a phone call saying, we have you on the schedule for Tuesday at 10:00. Well, he's at school on Tuesday. Okay...

[Pause].

>> PRESENTER: Are there any other options?

No.

Okay, I guess I'll see you at 10:00.

So... I think school is understanding that I'm open with them, if I can get him in school, he's in school. But sometimes we have no choice. Um... so that causes a time balance and a challenge in how much private therapy are we going to put him into because he certainly needs it. I don't want him to be using a wheelchair into adulthood, but he's also a kid. How much more time do we have to be a kid offer a family. So it's all a juggling act. Obviously we have language barriers with extended family. Long-term concerns for his vision because of that nerve damage on that side of his face. And just the emotional toll that it takes. We have an older child with normal hearing and normal health and -- well, physical health. But her mental health certainly suffers for things she's seen and experienced, even before she's old enough to remember. His first 6 months of life were in the hospital so she has that residual trauma of where is mom, where is data, when are they coming back?

So on that other side of it, what works for us? So we have found that committing to one communication option is not doable for us. He needs to have multiple options for how to communicate simultaneously. So that's why we worked hard for him to be in a total communication program so he has all of his communication options available to him at all-times.

Um, we also have to really work on setting boundaries which can be a challenge as an adult, for sure. With family, with um... doctors, with all the things. There are times with medical appointments that I have to say "no" that doesn't work. And then I have to wait for somebody to call me and sometimes they don't.

Um, thankfully our hospital has a program for us called Complex Care and so we are a signed a complex care nurse coordinator, and she helps do a lot of that behind the scenes that I can't do because I'm not in the system. Um, but even that, we were just having the conversation of: Can we have an appointment at 1 on whatever day? No we can't. I'm not going to pull him out of school to send in an appointment to talking about other appointments. So there's a lot of boundary setting, might not love it when they see my name in the e-mail but you have to do what you have to do. Therapy work for us. Scheduling is a challenge. I feel we have to be open with all the people that are involved in our lives. We have a huge village. We are very thankful and blessed to have it. And I feel like the best way it works is to be open about what is going on with him. And his timeline is his own. That's the hardest part as a mom because I like control, I like to know what is going to happen. I like to have a timeline and I've just been taught time and time again that I have no control over the timeline, this little guy is in charge.

Um... prioritizing school. School is a huge priority for us. Like I said, even, I'm definitely known to cancel or refuse a medical appointment because it's going to interfere with school. I think that contributes to his enjoyment of school, which contributes to his development, overall. And then sharing resources with our family, often. I often will forward e-mails I get about signing classes or other things like that, with our family. Not necessarily pushing it on them because that just creates more trouble, but making all those resources available and putting the bawl in their court for where they will take it.

So how can you help? Um, a big thing is to consider wheelchair accessibility, particularly if you're a professional and work in a clinic, there are many, many clinic settings that are not easily accessible by a wheelchair. Even the biggest most well funded hospitals in the area are not very wheelchair accessible. Even considering how your own office is laid out can make a huge difference. If it's difficult for somebody to get in there with a stroller, it's difficult with a wheelchair.

Accept all approximations if motor skills are impacted and the best way to find out is to ask. Don't assume that he can't. I feel like there have been many times on both ends of the spectrum where I assume that he can't do something but he's been doing it at school. Or school might assume that he can't and he's doing it at home. That goes back to communication. And make sure to communicate visually in anyway that you have to. Sometimes I notice that people can get self-conscious with their signing, which is fine. Some sort of visual communication can go a long way, just a picture for him.

And back to Andrea.

>> PRESENTER: Excellent. It's hard to -- the best ways to work with these kids is to listen to the parents. And see what is working for them at home and tell the parents what is working at school, or in your therapies. Um, but we will give you some research-based info. So differentiated instruction, differentiated, like she said, so when you're in the early intervention part of it, working as a village is really important. If someone is doing something, a certain way, and it works, wouldn't it be great if everybody on the team knew that so they could do it as well? Another thing is um, for IEP, IFSP development, ensuring no matter how multi-needs the child is, that their hearing concerns be primary or secondary on that document, because if they are not, then we are not going to be ensuring that whatever environment they are put in, is language rich. They need language rich. Because it needs to be as much as we can get in and as much as we can get out, no matter what the severity is of the other things that they are dealing with.

>> PRESENTER: In the IEP process when you have a kid with a lot going on, they really want to just stamp it as multineeds, on the IEP and I fought with them so much about that, because um... I needed hearing to be on there specifically, so that we can't skirt around the language piece of it.

>> PRESENTER: Absolutely. So, we have 7 minutes. I want to give five minutes for questions because I bet you guys have questions for Amy. So what differentiated instruction is. You might not be in the school system. You might still be working with them. But some of the -- in the EI process, but some of these things can still apply. Deny whatever you're doing around the needs of the child. Be flexible, whole group or small group, get them involved with others. They don't always have to be by themselves. What it isn't. Don't dumb stuff down, they are capable. We should be expecting from them what we expect from every student. Differentiated instruction is not meant to make people miserable. It's not mostly for gifted students, it's for all the differentiation going on in the class. It's not IEPs for all. Our students with disabilities can be in a general education setting and be a child with an IEP, and that doesn't mean that because the child is gifted they need an IEP it's for kids that need that level playing field.

Parents are key. They maintain consistency in the child's life. They help them maintain what you guys have taught them in your sessions and keep it going at home. They help with continuing either homework, or working with whatever session you -- whatever your session had in it, they will continue it at home. Who in here is an EI provider? Do you have the parent that treats you like you're a babysitter and leave the room when you come in?

Don't let them, say, we want you to see what you're doing so he can extend it, because he's got this. So make sure that they join you and work with him. Maintain communication, make sure the family knows what is going on. There should be no surprise. Provide activities that builds self-esteem and most importantly provide love and acceptance. That's what families do so that's what we want you all to do as well. All right, so let's open to questions. Do you have any questions for Amy? Or myself? Or in general?

[Pause]

There's one back there and then one here.

>> AUDIENCE: Thank you so much. Um... my question is actually about the verbiage of a child with hearing loss and additional disabilities because there's so many terms floating around. We had Deaf plus pop up and Gallaudet is now using Deaf disabled and now I saw your acronym, DW. The question that we have had floating around amongst professionals in Virginia is how do we decide which term to use? And it's difficult to sometimes asking the individual, depending on the disability. So as parents of Deaf children, with additional disabilities, what is your preference of the terms?

>> PRESENTER: Um, ask the parent. Just ask them. That's a big thing, radio I thought? So a lot of times, especially in the early intervention system, you have 95% of us are hearing. Right? So if you come in, both guns blazing with the term "Deaf" that might be scary. Hearing impair, you might gulp, but there's lots of terminology out there that pertains to whatever is going on here. What do you want -- how do you want us to refer to it?

And let the parent choose.

>> Regarding the specific mention of disabilities with Deafness, so I would say the same thing, ask the family. So it's hard to answer personally because I'm not a person who is Deaf with disability, I'm not a person who is Deaf, period. But I personally in my mom experience, kind of like the term Deaf plus, because plus is a positive word to me, and so I like the fact that Deaf plus, in my mind it's Deaf plus a lot of other stuff. But also, Deaf plus, like he's a talented guy. I think Deaf with disabilities is clinical, but that's just my opinion.

>> You should have told me that.

>> That's the thing. So, the reason -- so this is an old presentation that I have done with other parents who have more complex kiddos and the reason we called it Deaf with disabilities is because when I created it, that's what we were seeing, this plus was going away. Deaf was in the a disability but the other stuff was. So absolutely. I don't want -- it's never an intention to offend when we are trying to educate. Yeah, ask the mom, ask the family, ask the individual when they can answer that question. And go with that. To me, it depends on -- I've always -- my daughter was mild to moderate when we found out and lost all of her hearing within 4 years. But to me, if I wanted somebody to listen, Deaf had more power. So we used it and my daughter has never been offended. She's like "Whatever". She doesn't care. If we just say you know, use what the parents use and the kid doesn't seem to be bothered by it, then it's good.

Are we all done?

Thank you all for coming.

[Applause]

[ Session Concluded at 10:30 a.m. CST ].