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Deaf with Disabilities ‑ Parent Professional Perspective

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Deaf with Disabilities ‑ Parent Professional Perspective

>> Good morning. Welcome. We're going to talk a little bit more for those of you in here in the last session we're going to talk a little bit deaf with disabilities, and I have my co presenter Amy here with me. My name is Adrienne we're both with Illinois with the voice chapter and I work with school of deaf doing outreach training and consulting. Let's talk about deaf with disabilities and how many kids we're talking about 40 to 50% of our children that have a deafness category on IFSP have something else on their IEP or IFSP document but it may be more than that because many of our kids that have multiple disabilities may not have deafness listed at all. Important to understand we're working with a lot of families that have children with multiple things going on.

Amy and I both have children that are deaf plus or deaf with disabilities and mine is lesser than Amy's. She deals with a lot more than I do, having to know different things, all these different categories, but at the end of the day it's all a struggle, and it's hard. We're just going to talk about a little bit about what we see, we're going to talk about our own kids and we're going to talk about what we call differentiated instruction for those out there, educators, parents, differentiating instructions can work very successfully for our kids so we'll talk a little bit about that.

Did you know there are over four hundred syndromes that have deafness as a possibility symptom. That's a lot, right? So four hundred. Here are the most common that most of us are probably aware of. Washburg, kindred, stickler, charge, bore. (Phonetic) I'm not going to try to say that one and out port. These are the most common that we tend to see that are syndromic.

My daughter has large vestibular aqueduct syndrome that's prevalent as well. Some of the most common ones we tend to see are deafness, hearing loss with sensory loss disorder. We see quite often and attention deficit hyperactivity disorder ADHD and a lot of kids that have learning disabilities SE a well. They are the most common I tend to see and the work I do do on IEPs and IFSP. You may be seeing different things on your caseload but these are pretty common. These are the ones we see pretty frequently.

For me, this is my daughter Samantha who is 22 and graduating from RIT in May so super excited. She is profoundly deaf. She wears bilateral cochlear implants. She was born in 2001, and it was not mandated to have hearing screening although she did. Our hospital was a little more progressive and they did hearing screening however they don't know how to tell us and so they did defer and we probably would have found out sooner and we had her in early intervention under a speech delay so it took a little while.

At age 6 and 7 because she has large vestibular syndrome we knew the likelihood she was going to lose all hearing which she did and left side went first and 364 days later she lost on the other side. Let's talk about her. So she is ‑‑ she went to school all through elementary, junior high, and high school. Fully mainstreamed, had speech through about fourth grade. Now, she's a senior at Rochester school of technology. She does get services through NTID, so she gets captioning, note takers, and other accommodations that she gets through our IT for ADHD. She does have ADHD. She was diagnosed in third grade. One of the things we made sure we did was find a psychotherapist that understood deafness because we didn't want her misdiagnosed so the child went through hours of accessing and the teacher observed her in all of settings, just to be sure we weren't misdiagnosis her. If you meet her today without meds you would say yes she definitely has it.

She does have combined type so that's attention and hyperactivity. For her it wasn't hyperactive bouncing off the walls like stealing a teacher's pencil and saying inappropriate things. So we had to deal with all of that as a young adult dealing with anxiety, difficult time making friends. She is very aware of herself now and understand her needs, which is amazing. She contact teed us about a year ago and said, oh, I'm going to be going to Vermont, I met this person online. So her dad and I freaked out. Okay, you know, her name's grace, she's 22, she's become a really good friend and we're thinking it's a 55‑year‑old man. Well, grace and her have traveled around the country meeting other people they met online. For those out there, our kids find their people in different ways.

It might be scary to you but they do, kids with ADHD struggle with that. She is a chronic complainer. She will come home from breaks, and I listen, and I listen, and I listen, and then I finally say okay, I need five good things. You need to tell me five good things right now oh wise I'm going to be the one that needs to take a break or a pill or something. We know how it rolls, right?

The drive home is her, and I'm trying my hardest to not lose it and just tell me something good, and then she tells me something good. Then our conversation starts. She has difficult time finding silver lining. She believes everybody and everything is against her. She is getting better. We have seen a maturity spike in this past year so we're hopeful. She does have ‑‑ she defines friends way different than my husband and I do. Way different than her siblings do. She does not consider someone that she would meet for lunch once those are acquaintance and don't get the label. It has to be a person she feels deeply involved. Once she does become your friend she's very loyal to her family, very loving to us, very kind to us, so once you get her, she's well worth the wait.

ADHD is a very complex condition. Anybody in here willing to say, yeah, I have it. Anybody have ADHD? There are moments that are not easy, right? Believe it or I have it too. I have it I went through school without supports and I can tell you I would have benefitted from those supports it is neurobiochemical and parents do not cause it. No one causes it. There's nothing that can be done about not getting it. You either have it or you don't.

What can you do? Remember it's not a matter of being deliberately the way she is. It's not a choice. It's not part of her. It's something that has happened in her chemical in the chemical portions of her brain. Provide external incentives to follow rules. They like getting appreciated for doing things right. Give extra praise and encouragement. It can be few and far between for these kids because sometimes they may be problematic in a classroom so make sure when they are not that we are telling them you're doing amazing.

Follow a step‑by‑step approach. It's hard enough for our kids who are deaf and hard‑of‑hearing to follow multiple steps. Add attend can to it and it's even harder. So when we have teachers we must train them on understanding that multiple steps are difficult for kids that have hearing concerns, even more difficult when we're adding ADHD to the picture. Let the student earn special privileges. My daughter got to walk things down to the office more than any other kid because she needed to get that energy out. Alternate action with requests for attending. Consider adding spontaneous exercise into learning. We've had some good teachers over time. All right. Guys, it's time to get up and do some jumping just after the accident, and he would get up and it was so much better. It just got everything moving again, they were ready to sit down and attend. Minimize visual distraction when attention is required. It's the squirrel effect, right?

Any time you put a person with ADHD near something else, that something else is going to grab their attention. It's also that way. Provide listening environments for children who have useable hearing. Agree on small signals to help them remember to stay calm. They do not want to be called out. None of our kids do. Her fifth grade teacher amazing teacher, she would always just come and lightly put her hand on her shoulder to indicate that she was a little physical injury I had and it might be time to pay attention and Samantha knew what that signal meant. No one else had any idea what that meant in the classroom.

List parent help. Teach parents that they didn't do this and how they can help their students. Don't sweat the small stuff because if you do, you're going to be a barrel of stress. Capitalize on their sense of humor. My daughter is very much like her father, very dry sense of humor my parents are immigrant from Scotland if you ever talked with is someone from Scotland you really need to listen. Dry sense of humor. Listen to what they are saying.

They may be asking for help and you're not getting that signal from them so do listen to what they are saying. Don't take the easy way out. Make them get it. Say it and do it if they want it. Don't just give it to them. Make them write daily, weekly, and monthly to do lists. She hates them, but still to this day I will hear my husband on the phone with her saying, okay, well what's on her list and you hear her grumbling in the background but only way to make sure we don't forget things.

Give them a planner as soon as they can write. Provide a picture planner before that. We often will say, wells they can just do it on their phone or on their tablet. That writing portion of it helps them to remember. First, written planners. First and foremost, love them.

>> Okay, so my little guy is Evan, name sign Evan, he has a long list of diagnosis so I'm not going to read every single one but some of highlights are con gentle heart disease he's had three open heart surgery to date. If you're familiar with EMCO he was on that for eight days. Serious business. He has something called 22 Q 11 duplication syndrome. Which is I describe opposite of the Degeorge. One thing I just want to say conferences like these have gotten great at really representing some of the deaf plus like sub communities. CM charge syndrome which is great and I really appreciated this morning's plenary because eh haven't doesn't fit in think of those categories sits hard for families like ours to find community because so many different pieces. We do not have a standard template of kind of what to expected.

What they tell me about 22 Q duplication syndrome is that it could mean everything, it can be nothing, so, you know, that's super helpful. He obviously has hearing loss. He has one cochlear implant. No amplification on the other side and that's by choice. After the serious heart surgery and the amount of medical trauma he's experienced I'm not interested in voluntarily going under the knife again. When he's old enough but I and hi, husband decided as parents it's not worth it.

That's important thing to notice if you have families who you're like why if you think they should be doing something a certain way and they are not. There's a lot that goes into those decisions. Otherwise he has something called Horner Syndrome. One eyes is squinty. He had nerve damage during the surgery which effects the movement. Food allergies, using a wheelchair, transitioning to a walker. And he also has cutest darn thing syndrome so I should have added that.

He's currently five a kindergarten in self‑contained cluster program and he did three years of early intervention. He received PT, OT, two types of speech so one kind of typical. And then another that specialized in alternative augmented condition, and he had social work and nutrition. His school program utilizes total communication. He in particular favors signing over his other modes of communication. We've had to really train ourselves to let him drive the boat on that and tell us what works for him instead of us forcing him into something because he really ‑‑ he made the decision and that's what we need to honor. He has access to a device at school and at home. He currently receives PT, O T speech at home at school and professional to help him.

Some struggles motor skills inhibit his ability to sign clearly so you have to pay attention approximation in science. Sometimes fingers won't form the letters this way they are supposed to be formed. Medical needs as I mentioned earlier impact the cochlear implant. And his health can change quickly. One day, for example, at school he all of a sudden eye ballooned up. The school and I have to be in really strong communication with one another. So that we can differentiate between something that's not a concern and something that is.

Medically it's very challenging for me as a parent to strike a balance between having time for him to be a kid and having time for him to get services. A lot of people give me an interesting look especially professionals when I say that he does not have PT outside of school given that he's a child in a wheelchair, but for our family we decided for him to take swim lessons and gymnastic classes was more important for his development as a person for them alone in the room with a PT. A lot of decisions to balance.

Obviously as with a lot of kids we talk about at conference there are language and communication barriers with extended family. We have vision concerns over long‑term and just our experiences as a family medically have taken emotional toll on all of us.

What works for us? Using more than one type of communication option. I feel like that's something that I needed as a mom early on. I needed more information about total communication. I needed to know that we do not have to make a decision today and do that forever. Information is so important for us to try different things and be able to let him show us what worked for him. I really had to set some medical boundaries, so like the, for example, or sometimes I don't go to the audiologist every six months. I'm sorry. This is the wrong place for me to have said that. I need to turn back time a little bit but we usually go once a year and that's just me. Sorry. Sorry.

Therapy is something that works for us. Something I really wanted to mention is the us on the top of that slide because this is something that impacts our family as a whole. I do have another child a hearing child neurotypical and she has therapy too because there's a lot that goes along with it. Just a little plug for a program called (?) Shops and you can refer families she absolutely adores it and if I have to pick her up early she will be upset so it's a whole family.

Open communication don't hold back from me because you think I will be upset from something but at the same time don't hold him back. We need to have open communication about what's possible and what we can do because as the next one shows he's going to determine the timeline. I think I said a couple minutes ago he drives the boat. For me I have to prioritize school so I'm sure the people in hospital system who work in scheduling don't love me because I have to get him in school as much as I can which is not always easy with medical appointments and then sharing resources.

How can you help? Consider wheelchair accessibility. Medical facilities are very difficult to navigate with a wheelchair. I mentioned it in my previous session I have to do gymnastics to just get through the door so think about that in your office or place that you work. Accept sign approximations and don't assume he can't and obviously make sure to communicate visually. Differentiating instruction Andrea mentioned strategies of differentiating instructions many times when she was talking about Samantha. I'll try to point out as I go on too.

Differentiated instruction is lessons designed around the needs for students. I'm an educator myself and I believe that differentiating instruction is best practice in general, but it's student focused. Giving every student in the room what they need as a person. It requires flexibility and that's also another thing that's good. We know that just being in this conference is 25 sessions nice because I can get up and move. To sit in one room is not the way for anybody to learn. Individual tasks based on student needs so giving each kid what they need. Doesn't mean you're teaching every kid separately. Andrea mentioned the teacher just putting her hand on Samantha's shoulder that's differentiated instruction. That was her signal that she needed to redirect. What it's not is dumbing down curriculum. It's not bringing things down for kids.

It's not adding something on top of good teaching. It's good teaching period. It's not meant to make teachers miserable. There's lots of strategies that do not even require planning. Differentiating instruction is not for difficulted students or most challenged students. It's really for everybody. It's not just individualized instruction. That's an IEP. It's not IEP's for all. Characteristic of successful program is a can do attitude. Lots of instructor. Very specific objectives. You can differentiate and still have the same objective the same goal with a focus on individual needs.

Step‑by‑step instruction is important and individualized objectives. Routines are important that's a way to differentiate yourself kids who've appreciate what's coming and knowing prepared. When my more neurotypical daughter on high alert we can't learn that way. This is important thing as far as instructional materials else with kids at a lower level making sure to give them things at their appropriate age and not the reading provision of successful experiences giving setting kids up for success. Repetition to the point of over learning we know our kids need to hear things a certain number of times to be able to learn them. Finally, parents are key. Involving paints in the process is so important to differentiate instruction. Making it successful. Even just on the information piece, sometimes you see a different kid than parents see.

Parents might have an idea that works at home that can click. And the same in reverse we appreciate some things that work at school so we can make them at home. When parents and educators service providers are in synch with each other shows consistency and that sends a message to kids that everybody is on the same team in order to help me be successful. We can help students maintain self‑discipline. We can help with homework. Unless you get to that crazy math stuff. We can Google.

We can encourage good habits to help get them there and ready to learn. We need to be in communication of what you're seeing because of those things. We can give positive reinforcement we can boost up what you got going on and we can maintain communication and help them build some self‑esteem things and mental health to provide love and acceptance. If you have any questions. I think we're oh, two minutes over, I'm sorry. We're available and happy to talk here's our contact information and thank you so much. We're so appreciative of your time and listening.

[Session concluded.]

END TIME IN YOUR TIME ZONE – 10:09 AM (MT)

START TIME: 10:10 AM

END TIME: 10:37 AM