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Deaf and Hard of Hearing Lifestyle Changes: Real Life Considerations

Presenter: Michelle Hu, AuD

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Tips for Parents

- [Instructor] Welcome to this AudiologyOnline fast class. Please note that slides in this course are intentionally small to allow for the focus to be on the presenter and the visual demonstration. Please download the slide handouts prior to viewing the course so that you're able to follow along. Thank you and enjoy today's course.

- Thank you so much. Okay, these are my disclosures. I'm the founder and CEO of Mama who hears. I received an honorarium for this presentation. This learning event does not focus on exclusively on any specific product or service and there are no external sponsors for this course. Learning outcomes. After this course, my participants will be able to describe the importance of inclusion within a deaf and hard of hearing family, list choices for a deaf and hard of hearing families to make and empower their village and explain examples on how to adapt family lifestyle to being a deaf and hard of hearing family. So this is a presentation. Typically, this is how I would counsel families. This is the way that I speak to deaf and hard of hearing families, parents and family members.

So I know that most of the audience will here at AudiologyOnline will be audiologists or students. So please take in mind that this is how I'm going to be presenting the information towards the families and this is how you could get information and tips and techniques on how to talk to your families that come into your clinic. Journeying as a deaf and hard of hearing family. I believe when you have a deaf or hard of hearing child or a family member so when somebody in the family is identified with or is experiencing a disability and it can definitely affect more than just that person and the person is part of the whole family thus the entire family is affected.

Therefore, if you have a deaf or hard of hearing family member you become a deaf and hard of hearing family. And I feel like best practice and optimal inclusion is when all family or community members are and feel respected. They have a sense of belonging and they're able to participate if they want to, to their best ability. So even from a

young age, you can never start too soon. You can start as soon as your child is born or identified or if you know somebody has a disability or is experiencing exclusion or just not feeling like they can participate fully in the family. My name is Michelle Hu. I'm a pediatric audiologist and I'm founder of Mama Who hears.

I grew up with a progressive bilateral sensory neural hearing loss, secondary pendred syndrome and enlarged vestibular aqueducts or EVAS. I was first identified with mild hearing loss when I was about three to four years old and by age 10 years I had a profound hearing loss bilaterally and today I utilized bilateral cochlear implants. I grew up in a household with two parents, my mom and dad and one older brother, all of whom have normal hearing. When I was identified, my mom was very surprised. As a three to four year old, I was constantly communicating in spoken English and I could understand two dialects of Chinese that my parents spoke in the home. As my hearing progressed from EVAS it got more and more difficult to communicate and navigate social situations.

Looking back, I saw myself shrink back from group conversations during lunchtime at school, I stopped going to movie theaters. I don't think I went to movie theaters for about 15 to 20 years maybe. I always had my nose in a book that was direct communication for me and I only spoke on one very loud phone with my mom as I wasn't able to understand even my dad's voice on the phone or my brother. When I was young my mom did all of the appointment scheduling. She was my alarm clock all the way through high school and my best friend knew to sit on my right side as it was my better ear. I advocated. But accessibility and technology was definitely not as readily available or advanced as as it is today.

I do believe because of how my parents worked together with me practicing and having such a wonderfully supportive village within my hearing healthcare professionals at my school, the principal at our community center, at our church, I grew up to be a

very strong and confident advocate for myself. I'm much more comfortable communicating verbally now with bilateral cochlear implants. But prior to receiving the cochlear implants as a hard of hearing adult I can't tell you how often I would rather drive to a medical office and walk up to the front desk to talk to a person that I could see to schedule an appointment as opposed to calling, dealing with missing information asking for repetition, getting embarrassed or I would just say yes and I wouldn't know what I was saying yes to.

Audio phone calls without any visual visual access in the form of live captions, FaceTime or video services or interpreting services are just a nightmare. I would personally rather not have an appointment, not pay for or receive a service or go somewhere else. So how can we do this within a deaf and hard of hearing family with a heart of hearing or a deaf child? Of course, we want to be inclusive for all of our family members, but what does that look like? Well, first section, we'll talk about tips for parents. First, sit down with your partner or your co-parent and have a conversation. Discuss the feelings, the emotions, the ideas, what kind of impressions or opinions that might come up.

Get that all out in the open. How does it feel to have a deaf or hard of hearing child or a family member? Who or what would you like to blame or thank if necessary is not the most common feeling. But some parents actually feel relief and almost triumphant because they say, I knew something was going on and the healthcare professionals kept on saying, no, everything's fine. Everything's fine. So when they get that identification or diagnosis they might actually be feeling triumphant or relief. It's important to recognize, acknowledge and process these emotions because how a parent feels about their child's deafness will definitely shape how the child feels about their deafness themselves as they grow up.

So getting on the same page regarding family lifestyle, communication style and how do we work together as a team is very, very important. How do we want life to look like for our deaf and hard of hearing family? It could be looking at core values such as fun, authenticity, quality time, family. The core values will absolutely help pave the way to the goals that you set as a family. Other things to talk about? Would you like to learn sign language or cued speech as a family, take classes together. When you take a look at that what avenue would be the most feasible at this time? Do you have more younger children? So maybe virtual classes would be a great option.

Would you like to connect to a deaf mentor? Do they come to the house? Do you have to physically go see them? Do we understand what and how much our child can hear? Perhaps assigning a medical point person, one expert in the family that would take care of scheduling all of those appointments and then relaying that information or maybe putting it in a binder so that the rest of the family can understand what they need to understand versus everybody being an expert in the family. So it kind of just starts at the top. You can set the tone for how your family takes on that deaf or hard of hearing journey. Let's see. I talk about different things with connecting with your healthcare and healthcare professionals.

Talk to your audiologist. Listen to a hearing loss simulator. There are a few online but I would definitely talk with the audiologist. They can input their exact thresholds into the hearing loss simulator so that you can really understand and experience as close as possible what life may sound like for your deaf and heart of hearing child. Professionals are supposed to be the people that you can go to with questions, concerns and issues to be helped, served and supported. We take a look at environment in the home. What does that look like? Is it deaf or hard of hearing friendly? What is the seating arrangement like in your kitchen or dining room? My request for our home when we were house hunting was an open kitchen and a living room that's seemingly like all in one room.

Is the lighting well placed or can it be adapted? Do you gather as a family? Are meals very important to you? Will sign and cues, visual cues be well received. Are closed captioning or interpreting services available to be on the television or on the computer? How are your couches arranged? Can you bring in alert systems, visual smoke detectors, visual alerts for doorbell phone call or how can we get ahold of each other? Phone relay services, video phones. Take a look into getting all of this equipment, what is provided for by the government or what other ideas do you have? Like smart light bulbs. I have a deaf family that installed smart light bulbs in all of the bedrooms and with an app on the phone they can make that light bulb flash so that they can get ahold of their teenagers when they wanna give them a message.

Taking a look at the schools as a parent or with your co-parent, getting to know your educational audiologist, your teacher of the deaf or disabilities counselor. In the community, safety, consider safety. How do we keep our child safe? It really takes a village. ID bracelets that say what's going on with them, what they may need. Contact information, conversing with your school personnel and even at parks. Go ahead and talk to the ranger at the parks or in the kiosk where you might check into the park. Let them know you have a deaf or hard of hearing child or a family member so that they are aware. Also calling the police and fire departments to let them know that you're a deaf and hard of hearing family so that you can utilize other avenues to communicate in worst case scenarios.

Talk about these worst case scenarios. They might have suggestions such as wearing certain color clothing or a vest or lights as a family. Also take a look at financial planning. Are you able to set aside money for potential accommodations, devices, or services? Take a look at insurance plans. Reach out to your state or local governing office to find out what accommodations they can provide. Family planning. This is the last part for the parenting that I have. Take a look at genetic testing. Talk to your ENT

as the parents or test the child. It depends on the etiology and the nature of the hearing levels. So if it's not specified, sometimes it is you may want to go into some extra blood or genetic testing.

Do you need to know will it affect the change of your outcome of how you approach this journey? Some parents are different. Get on the same page about that with your spouse or your co-parent and know that your child is still the same the same as they were born and now they are who they are as a diagnosis. Spend time with your child and let them lead a play session. Observe how they react, what makes their eyes light up and look at life through their eyes. They're definitely not living your childhood. And if you choose amplification I absolutely recommend you spend time with both of them with and without their devices. So you can see a little bit into their eyes what their life is like. How they're living and these windows that they're experiencing life to. Life through that is it for the parenting part.

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Tips for Siblings

- Okay, now let's talk about siblings. Part two, honor and respect. I recommend highly honoring each sibling for who they are and who they are not. Just because someone is an older sibling, just because they have typically developing maybe no disabilities of any kind doesn't mean that they don't deserve the honor and respect. So I would incorporate some team building exercises or scenarios into the family. Talk to the sibling, ask them how they feel about being a deaf and hard of hearing family. What do they think of it? What does it mean to them? Do they understand what's going on with their sibling? And you can keep it to simple terms when they're younger. But allow them, give them the honor and the respect and allow them to express frustrations of having a sibling who maybe they go to so many doctor's appointments, maybe they get more mommy and daddy time than they do, and they're a little bit jealous.

Allow them to express those feelings and like where it might come from. And it could open up a whole conversation of learning about their different love languages. Maybe they need more quality time. Maybe if you brought a flower or you know a picture that your child drew during that appointment home to that sibling, they would feel that love. Like, oh, they were thinking about me at that appointment even though I didn't get to go. I had to go to school. Or I went to a play date. And why perhaps the family might turn down an invitation to go see a musical performance or something when we find out there's no deaf or hard of hearing accommodations available there.

But honor that perhaps maybe that sibling wanted to have a birthday wish. They really wanted to go see that show. And you know, it's not fair that we can't go as a family because so-and-so won't be able to hear. How about they could honor that wish by saying, all right you for your birthday you get to go to this show just with mommy and daddy that day. So they get a specific date with their parents and their wish still gets honored. I recommend role-playing and practicing scenarios. This was very, very helpful for me when I was younger and I'm realizing it now as an adult. When I was in

speech therapy, when I was in school talking with my, she wasn't a teacher of the deaf but she was I think a disabilities counselor.

She would role play different scenarios for me and it would give me the dialogue, the vocabulary, and the processing or practice of what do I wanna say when somebody asks me what are those things on your ears? What do I wanna say when somebody is like, uh Michelle just can't hear, ignore her or something like that. All of these different scenarios, role play them and practice so that that student or your child can sit with it and see how it feels on them and they can eventually choose you know what this is, this is my answer. This is how I want to come about in school. This is how I wanna react in that situation. So practice in their shoes.

I would recommend the siblings to practice in their deaf or hard of hearing siblings shoes or and practice in their own shoes of what they want to do or what they want to say. Oftentimes siblings get protective of their deaf and hard of hearing sibling and you know, they try to protect them or take care of the situation themselves and it might not always work. So if you bring in that sibling, maybe they can say you know what, no, I wanna say it for myself. Or if the older sibling who may be typical wants to say something you can discuss, okay well you take care of it but what do you want me to do when I know that you didn't hear it?

Do you want me to tap you on the shoulder, they said something or do you want me to find out, or do you want me to tell you what they said, or do you want the original person to say it for you? Involve the siblings in the processes as much as you can. Now, I definitely want to acknowledge that parents might not be yet ready to talk about this with their siblings but when you are involve them in the process have them have them come in to doctor's appointments or therapy appointments if they might have the time or if you have to bring them in, allow them to get excited. And you would be very, very surprised with siblings coming up with so many different ideas and their creativity

is definitely sparked and it's a lovely creation of a bond between the siblings versus we're doing this for this sibling and this for this sibling.

And you guys are gonna grow up separate because you are so different. When you can identify and come together as a team with their siblings that create so much more of a supportive village within your little family unit. So just giving them vocabulary, giving them the practice discussing how to deal with unwelcome responses and choosing a dialogue that you can use to respond to the family. Devices, if you choose to utilize devices show the siblings how their remote microphones work. Show the siblings how the hearing, if you trust them, how the hearing aids works so that they can help support their younger sibling if needed sometime in the future. I remember teaching my husband how to change a battery in my cochlear implant processor.

And it was, first I was nervous 'cause I'm like is he gonna break it? What is he gonna know what to do? But there was a couple of times I was driving and my batteries started dying and I was like, oh hey, can you do this for me? I could focus on driving. He did that for me and then I didn't miss any of the conversation that was going on there or whatever environmental sounds that were occurring. So it was great. Learn and teach the siblings signs for their favorite animals, their topics, their games. You'll be surprised how much they'll get into it. And it's not like the deaf and hard of hearing member of the family has their own life, their own language.

When you can bring it all together it creates such a wonderful and supportive team. Practice at home, role play different ways of getting that deaf and hard of hearing family member's attention. Either you know, flashing the lights making sure you're putting, you're tapping them on the shoulder or stomping on floor if needed. And role play in both shoes. Like I said, I have them role play as their sibling as who they are and even as that deaf and hard of hearing person so that your children, other children can absolutely understand what's going on for them as much as possible. I also highly

recommend assigning a buddy system in case of group activities or emergencies. When you go over what to do in case of a tornado or house fire, assign you know Sally is gonna be Eddie's buddy.

Make sure that Eddie hears or wakes up when you hear the alarm. Before you go to Disney World, assign a buddy system then you can make this as a fun playing game. Like when we go for a walk, assign a buddy system and they will naturally just know how to support and take care of each other over practice. And then going back to family planning, genetic testing of the siblings if needed. I definitely recommend getting based on an audiograms and routine follow up if appropriate. If your etiology of the hearing loss or disability is genetic. And that's it for the siblings section, section two.

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Tips for Extended Family Members

- Let's talk about Extended Family, Part Three: Challenges. I think we all know that it can be very difficult to navigate anything let alone a deaf and hard of hearing journey with extended family members who may have opinions, thoughts, concerns, and want to just be supportive. So, it can be very difficult to communicate with them in the way that you want to or getting your intentions across. Know that they may never understand or never agree with the choices that you're making as your family leader. What I would recommend is to provide information from your professionals for your extended family even if your extended family needs to be involved or if you are close with them. If you're not close with your extended family then maybe this isn't a conversation that needs to be had.

But know that this is your child. You are the parent, you are the legal guardian. But providing information from your professionals such as your audiologist, your early interventionist, teacher of the deaf or deaf mentor can be helpful as it takes it a little bit away from you. This is the information I got from the professionals. They are the experts. This is what I want to show you. So if you take a look at this information, it's not coming from me, my opinion or my thoughts of how I'm parenting. This is where I'm getting my information and this is where I am feeling empowered to make the choice around whatever choice or decision that we're making for a deaf or hard of hearing child and family.

Build a strong team with your co-parent or your child's other guardian if they have one. Have your own or the same story together with what you want to say to your extended family and established a we language. We as a family, we've identified our child as deaf or hard of hearing, or deaf or hard of hearing, whichever choices that you wanna make. What this means is use that kind of language or we've explored many options and as a family, we've chosen to. Hopefully that helps what your extended family realize, "Oh, they're a family unit. They're working on this together as a team. Who am I to be on the outside to express an opinion or tell them what to do?"

Most of the time, deaf or hard of hearing children are born to hearing family. So, not everybody knows what to do on that deaf and hard of hearing journey. I definitely recommend having a show and tell, empower your child or empower your extended family to, "Oh, what is that? What do I do when I see a hearing aid on the floor? What do I do when I see a cochlear implant processor stuck to the refrigerator? I don't know how to handle it." Let them take a look at it, play with it, and know what to do so that they can be a little bit more confident in what to do if, say, if they're babysitting or if you're having a family gathering.

But just know that they may not always agree. Know that they may not understand where it's coming from and be okay with yourself. You might still be processing as a family, you might still be figuring it out. But give out information if you feel comfortable with it. And do it from a we language point of view. Do it from a we are a team, we're taking a look into this. We do have a supportive village in terms of our hearing healthcare professionals or deaf mentors, and we want to do that as a family. Take a look at physical space considerations. Most often we gather with our extended family around food, around restaurants, around the dinner table.

Consider circular tables, corner seating in restaurants, maybe ask the restaurant for a private room so that as a deaf and hard of hearing family you can create that inclusion, that optimal inclusion. Ask if you can lower the music, brighten the lights, and just take a look at the acoustic. Oh, this playroom or this play date area is just too loud. Everything is hardwood floor. The ceiling, everything's echoing in here. It's not a great situation for our deaf and hard of hearing family member. Could we get a rug in this room? Could we go to a different spot where it's not so noisy or they will turn the music down for us. Offer visual cues and aids.

Everybody benefits. Make a request. Could we have closed captioning on the movie that we're watching as a family? It will only help everybody. It will promote reading with your young one and give more cues for a person who might just kind of be glancing over at the TV. They know what they're saying and there's just so much music or yelling, going around. It's inclusion and if it's what you want, request that your family ask you what you want to do. Start from the beginning. I highly recommend a intense onboarding. So, I had a family that was going to a new school. They had all of the teachers, the principal, and they also include the janitor in the meeting of who is this deaf or hard of hearing child that's going to come to our school?

Why is the janitor important? Because if he were to see a hearing device or something on the floor, he would know what to do with it. He would know who to bring that to. He would know who to alert. So, an intense onboarding of everybody in the family, even someone you might not think is essential or important or has a position in that school or area is important for them to learn about it, and know that your family is the perfect family for your deaf and hard of hearing child. Everyone is a part of that village and everyone should get that education. A family point person, this is my last note on family, is assign a person, it might be just parent or a co-parent to talk with that extended family.

For example, my husband is the go between with me and the kids or my side of the family with his side of the family. We've established, you know what, you're the person who understands your mom and dad a little bit better. How about you be the person to relay that information or if it's about food. All right, Michelle, you talk about where we're gonna eat, what we need and just make a list and send that to my mom. Just have those conversations of who that point person might be. And that wraps it up for extended family members. If you have any other questions regarding today's topic or would like some other information or any personal questions, I'm reachable three different ways. My website MamaHuHears.com. My email is

DrMichelleHu@mamahuhears.com. And then my Instagram community is, the handle is Mama.Hu.Hears. Thank you so much.

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