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CONSUMER: CASEY JUDD

EHDI

NARITA A/B – 13 “LUCKY” WAYS TO BRING PEDIATRIC HEARING AIDS

MARCH 5, 2019

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>> I'm your room monitor Jane if you have any concerns about room temperature or anything you can let me know. We will end promptly, and I will ask you for your evaluations as you walk out the door unless you're staying for the Iowa medicaid then you can keep it. Otherwise we will learn more about legislation. Thank you.  
>> Hi there, welcome, my name's Andrea and Corinne and Lesa and are talking about participating in legislative efforts in your state. A show of hands how many of you are working on getting legislation in your state. There's no coverage at all. Okay? The, right, okay, so some might be in transit. How about those of you who are here that have legislation in place that want to reflect on that and make it better, make it stronger, up the ante. The rest of you guys have ‑‑ gotcha. Okay. So we have no relevant financial, non‑financial relationships.  
>> I'm Lesa Coleman and I have six children. Two of whom have hearing loss and two of ‑‑ both of these girls are here with me today and they participated in this process with us. So happy to be with you.  
>> And my name is Andrea. I have three children. My two youngest were born with a hearing loss. In my former life I was a pediatric and worked with kids with medical issues and it was not not on my radar when my ten pound son referred I was shocked he was diagnosed with a hearing loss. I call it the trifecta of losses. You get the diagnosis. It was difficult I will acknowledge for me to have him wear hearing aids and the final assault was when my husband and I were dually covered and neither of our insurance covered the hearing aids. When my daughter was born with a hearing loss I knew it was genetic and I wanted to know what cause it and my kid's hearing loss is due to usher syndrome type 2C not only will they have the hearing loss to deal with but the later onset vision loss as well. I was one of the core members on the Idaho legislative team. In 2012 when my daughter was two and we were looking at two sets of hearing aids for life I tried this process, the legislative process, got what I'd say a ripple, a wave back then. But not enough galvanization, lots of different reasons, we're not sure why, but it didn't have the impetus back then but it does now. So ‑‑  
>> I'm Corinne Coleman. I had moderately to severe hearing loss. I wore hearing aids since I was two years old and I'm currently studying audiology. I've been excited to give back. I'm part of the Idaho process, I'm working with Utah and their legislation process as well because it's something I'm passionate about.  
>> Today we're wearing lucky green in honor of St. Patrick's Day coming up and the idea of lucky, really there are some lucky things that happen that truly there's a lot of things that you can do to move beyond luck to help get legislation passed in your state and we're going to cover 13 and we hope maybe some of these things will be helpful to you. One of the first things we were playing Schoolhouse Rock as you entered and I am embarrassed to say and I didn't want to admit it for a little bit I had kind of forgotten the process since my high school government class and it was very helpful for me to review I know that sounds silly but they take the bill to the House and the Senate.

It's just a good review of the political process because of course you're answering into a political process. And to get legislation passed of course it's political.

And you ‑‑ it's really, will behoove you to understand the process and each state is a little bit different. Texas I believe their legislative season meets every other year where Idaho is annually. And so you want to know some of those nuances but it really did help me understand the drafting of the bill, and and then proceeding forward.  
>> To add onto that, doing your homework. What's the current law on the books? What do you actually have there for in terms of hearing aid coverage or Bajas or cochlear implants. What's actually there? Being able to know that. Most states you can research this online just go to, Utah.gov. Something that was beneficial to us was calling the legislative library and they can actually look it up for you. Which is really nice. It's hard to navigate the codes and understanding laws and just the language of it is very confusing. Start collecting, working with professionals and collecting past appeals. What has been rejected if you're parent, have you actually had a letter from the insurance company that said, no, I'm not covered or this. And start collecting those stories and collecting the reasons why they're denying coverage. And, again, like Andrea's stating she tried several years ago to do this and starting to gather those people and what has already been done so you're not backtracking or making the same mistakes or things like that.  
>> I want to add here that we determined in Idaho that there was legislation, the reason that we had not been getting funded is there was an exclusion and a lot of times hearing aids fall in an exclusionary category. They were excluded but there's another subset of rules that often covers congenital losses. We were very surprised to understand that if we would have made an appeal on a congenital process we probably ‑‑ our ‑‑ we probably may have been able to successfully appeal because there was a conflicting law and when we were able to recognize that as patrons and represent that our representatives saying there's a conflict in the law. They say, oh, let's help you fix that conflict.

So I recommend that you look carefully at your rules, there's probably an exclusion but there's probably a congenital piece that could, you know, that looks conflicting. So look carefully at your rules.  
>> But that's not to say to keep pushing for legislation because as one of our parents here her daughter had bacterial meningitis. So you want to develop an elevator speech. A really galvanizing one that's two minutes or less. If anyone's familiar with that elevator speech where it's quick, to the point, the salient things you're trying to get across. Just the facts. Not rambling on and stand and deliver. This was actually a group of, most, all the time it was a group of moms who had some pretty galvanizing stories mine with the vision part later on and I went back to school and became a teacher of the blind. Another mom her daughter almost died of bacterial meningitis. We brought ‑‑ I brought pictures of my children, Kylie, when she was a baby with her hearing aids to show them, yes, babies need hearing aids. I showed them the insurance denials as a visual for them. Lesa brought in a huge box of ear molds and hearing aids. Anything you have to augment your speech is going to add to it. I actually brought in my ‑‑ I have an older son who does not have usher's syndrome. His education file on the desk is this big and my other children's are this big and I said this is what us moms are looking at.  
>> This is going on statewide too. As much as it impacted me we figure at least 40,000 dollars out‑of‑pocket in this box of tools that we used. But it impacts everyone across the state. In terms of developing an elevator speech and contacting local representatives this really came to a head when our representative said this isn't going to get passed unless you talk to a republican representative and I thought in my mind I need to talk to my local representative I know him personally and it happened that I was leaving the statehouse and down came my representative and I had to stand and deliver. He had less than two minutes and I said we need a sponsor, kids can't get coverage, I can't buy writer, nothing. With that two minute speech he said I'm in, I will sponsor you, talk to me later. Good‑bye. It was so fast and you just need to be ready to give the salient points at any moment so be prepared and I think we reviewed all of that. Asking to meet in person also and don't limit yourself to just your representative. As we're going to talk later about building a team, having multiple representatives is really important. I kind of thought, not that you need one sponsor, cosponsor, no, in Texas they informed me that they had lots of sponsors from the House, and the Senate, that they had talked to lots of different people who are informed about this and that's really also helpful because when you go to testify in terms of, you know, making a testimony in front of a committee and especially the health and welfare committee there are going to be representatives from all over the state and anybody that you already previously contacted really will be informed and be ready to support when they need to make a vote. Don't limit yourself and let your people across the state and on your team contact the people they know. This is a good thing. At least it was in Idaho.  
>> So go and get that core group, that parent basis core group that can commit to meeting without a lot of time which does unfortunately, you have to have a flexible job or a flexible life that you can be there when they need it. That parent base is super duper powerful I think when I started I was the solo one. I gathered a lot of e‑mails going on. We had a good group of people. Multidisciplinary. Fortunately on our team we have a speech pathologist whose son was born deaf. I'm a nurse. One of the ‑‑ going into audiology. One of our audiologists has a southern with ‑‑ son with hearing loss.

We have a lot of people on our team that can speak to the brain process. If you can find those folks that can be really instrumental. Given that advice, that testimony, that evidence‑based practice that is so critical. Schedule meetings in person or on Zoom. We want to make sure we represent those in Idaho. So one person cannot do this alone.

It's a huge process. If you guys have had failed in the past or some of you said you're redoing it. It's never the same river twice. Keep that in mind. Keep persevering. Keep pushing through. It'd be wonderful if every child in this nation could have coverage. Use Hands & Voices. Have members talk to their representatives, so get out those e‑mail blasts through Hands & Voices whenever you can. These are pictures of us up here in the top left. It's kind of our first meeting. Top right is one of our last meetings and then that bottom one we were jumping for joy because we had a huge milestone. That's my daughter. Bring your kids. Kids are really powerful. We have some amazing teenagers give testimonies and that is huge. If you guys went to the first plenary session you heard about Pando, that tree, that is many roots in one voice even though we were the core we had people from all over the state giving us information.

So I just thought that was a way to kind of look at that. Be ready to go at a moment's notice so we knew ‑‑ has anyone done the Tilt‑A‑Whirl at the fair where you're about to spin and you lean to the left.

That's what it feels like and you get that momentum going. We needed to send letters of support to the department of insurance. I cut and pasted that to every single contact in any phone and asked, can you please do this and quite a few were able to do that. That's the kind of momentum you need to take and keep propelling forward.  
>> Set goals and expectations. When we ‑‑ a bill had been drafted by our representative. And she just had given stab at it. We wanted some salient things represented. We said these are the things we're going to try to be nonnegotiable on. One was coverage for children 6‑21 years old. A lot of times it stops at 18 and there's no reason for that. It's just a pattern that's there we don't know for what reason. But all other childhood disabilities, illnesses any durable medical equipment follows that child until age 26 when they leave their parent's insurance policy. I highly recommend that you put that in there and we'll show you in a minute the clause that came with and how to just put it in without even stating an age and then the law assumes age 26. That is a goal that we set and we also as reviewing everyone nationwide we wanted at least 3,000 dollars every three years per hearing aid. That was important. We wanted congenital and acquired losses to be covered. So of course as we talk today unilateral loss those develop later. We wanted to also define the hearing devices so that no child would be discriminated against in this provision because of the type of loss they had. So that mild unilateral would be covered just as well as a profound bilateral loss. And ‑‑  
>> You're really educating these folks they did not know about hearing loss, BAHA, bone conductive versus sensorineural. People want to learn about this. You have their attention to educate them about this issue. And.  
>> And then we wanted ‑‑ we thought it was a pie in the sky kind of thing but speech and language habilitation. If you get knee surgery you'll have PT afterwards and we thought it was important for obvious reasons so we asked for that.

And in every testimony we gave we spoke to that and we made it known to our representatives that that was something that was important to us and so in ‑‑ here's our rule change and it became a rule change and not just a new piece of legislation but we did get the goals that we set out to accomplish. So all devices are covered, hearing aids, the BAHA, the professional determined devices or cochlear implants. Examination for fitting them. Going down, one that's not highlighted covered dependent child. So that's ‑‑ the 0‑26 covering not less than one device every 36 months so we didn't need to put a limit. So there's no limit on our bill so we got more than we thought we wanted. And not less than ‑‑ and we did get 45 language speech sessions and just be prepared and we thought we would be asking too much but they were ready to help us.  
>> Get bipartisan support. It shouldn't be a partisan issue but it's helpful to have both sides representative to you. We had Illana, Pat Macdonald, Idaho is a republican state so having both factions there is going to be really important. Educate multiple legislators. We testified on the health and welfare committee. The House ways and means and business and commerce so we hit all of those areas and these representatives they want bills passed that's like their accolades for doing a good job.

They represent you, they work for you and they have a vested interest in getting the bills done. This is their campaign, they're campaigning the whole time and this is what their work that they've shown they've done.  
>> It's interesting every state you go will have different opinions of this. Just to reemphasize the importance of reaching out to all the representatives that you can. Getting all the support that you cannot just one black or white, red or blue, you know.  
>> A bill versus a rule change in republican states, just, you probably already know this but I, again, the political process, they don't want more bills. They want ‑‑ it was much more palatable to them to have us change something that was already there or just make adjustments. Make a rule change and so we had to come through with a House resolution for the party to study it. At first I was disappointed thinking we didn't get the bill, but we were instructed some political ‑‑ as we met with the chair of the health and welfare committee said this is what I want you to do. Come through with a real change and you'll get it but if you try to push it as a bill we'll all say no. In the republican states be wary of that. A democratic state might be different. And, so then the Department of Insurance took over here.

So, okay.  
>> I'm going to fly through the visuals and communication. We emphasized how important it is to have a handout. Something to give during your elevator speech. What can you give the legislator you're talking to so the main important thing. They want to know the facts, what is the issue, who does this effect, what is the cost, what are the consequences, right? This is what we started with nice cute pictures. It looks nice but we just realized the print is small, the wording is not as good. And quite frankly it wasn't very effect effective ‑‑  
>> This is what I ‑‑  
>> I thought it was like whiny kids and I can say that because I ‑‑ okay, keep going.  
>> Yeah. Another important reason to collaborate with other states we got this from Texas and it was amazing because it just very clearly states what do we need, what's the impact and the cost and everything so I actually went and showed this to Utah and they already had the right side. It was the two side brochure but we were able to readjust what we had and it's amazing how much people appreciate the facts in the states. This is the website for those in Utah or anyone can look at it. Letutahchildrenhear.com. That's also incredible. Use websites for people to gather. You can use that as a reference as well.  
>> I was surprised how every time we went to testify they wanted to give a little card. Every single time she wanted to pass it around to all the people in the committee and I, so be ready with a good flyer. Okay?  
>> And that infographic is kind of like your two minute elevator speech. So to the point, right there.  
>> This is a really important piece.

Know the state statistics. Every meeting we went to every time we testified they wanted to know how many children are receiving deaf and hard of hearing services and how many children are covered under medicaid. In our state it was 40%. We were talking about 60% of the children with hearing loss in our state. This, if we would not have been able to stand and deliver these statistics, several times we would have been pushed back or said, oh, come back to us later when you know what you're talking about or when you know how this is going to effect our state. Be ready with all of those statistics. This is something from our ISDB program. The numbers are already there. You don't have to reinvent the wheel, and they were happy to share this was the total of 1600 kids in our state, and we could represent where they were regionally. This is probably in your state and it's good if you have one.  
>> You want to make sure you collaborate with states or at least look at the legislation. We looked at Texas, other places, if you're from California, I think Oregon has passed legislation so look at them because they're a democrat state. Use the website. EHDI state legislation on infanthearing.org you can click on every state however I don't know if this is current because I get AG Bell information and Georgia actually has an increase, they passed one in, it might not be up‑to‑date because AG Bell from August 2016 to Georgia to increase their coverage. It's not on this map but this can give you guideline. It doesn't have Idaho so again I'm not sure but it's a good one to reference to look at all the states as a domino effect. Look at all the states.

This was from Texas and this is a fiscal notice from Texas which we believe has a ‑‑ maybe the largest number of kids in the nation with hearing loss and wearing hearing aids and different devices when they did the actuary numbers on this the impact to insurance is less than 10%. Am I doing this right? No. 1 tenth of 1% to the premiums.  
>> To the premiums ‑‑  
>> Of how to unpack them.  
>> There was no fiscal impact to the state of Texas. This was helpful to us in Idaho because we're the small state if Texas has no impact Idaho would have no fiscal impact to the state and that was important evidence and they, you know, were concerned about numbers and when we were able to hand them that paper they said, question over now we'll move on because we'd done our homework and had these pieces of information from other states they moved on.

And Texas is the same political climate as Idaho. They said, okay, Texas has done it.  
>> People don't ‑‑ I don't want my insurance premiums to rise because of this and there was no impact at all.  
>> It's really important any again there was five to seven of us who were very consistent. Know your audience. One of the ‑‑ the moms who talked, always called her daughter's hearing aids brain development devices. We got to point the that we were growing these brains. Carrie talked about her daughter almost passing away due to meningitis. I talked about my children's dual sensory hearing loss. We had a teacher of the deaf who came and testified and also wears hearing aids herself and saying she can spend more time instead of finding funding for hearing aids but can teach the kids. We have a big diverse group of people.  
>> I think we are getting a sign that we have to cut it off but if this is available on the EHDI site and will be afterwards. If you have questions, I think to ‑‑ a final thought is just always express gratitude. Everyone that you're talking to. Everyone, you're going to raft with, they wrote handwritten letters.  
>> Yeah, I just sent out a Hands & Voices blast and asked for parents and children to write thank you cards. We are very indebted for this. I think being humble and kind goes a long way in this world.  
>> When we go to testify we say thank you for listening to us. Never go in with a negative attitude. Thank you for coming today.  
>> If you want to meet we'll be available and here throughout the conference. And this is our information as well.  
>> You can text us our e‑mail us.  
>> During lunch we'd be happy to meet with you and if you have any questions go out into the hall. Oh, do we have time for a question or two? No. Okay.  
>> If you have a question, come see us in hall. We're in green.  
>> Okay. Thanks.