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Not our First Rodeo, How Hearing Aid and Cochlear Implant Legislation was Finally Passed in the Lone Star State

3:35p-4:05p

Casey Judd

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>> Okay, we're going to get started. This session is titled Not our First Rodeo, How Hearing Aid and Cochlear Implant Legislation was Finally Passed in the Lone Star State. You have evaluations on the table. I'd ask you fill those out. They'll all be in the back, you can hand them to me at the end.

>> Maybe that rodeo thing doesn't work too well for Colorado, but we're in the midst of rodeo season in Texas and it's a big deal. When we say something has been done over and over again, we say it's not our first rodeo. That's where that came from. It took six years to pass this Texas legislation.

Let me tell you about Texas ‑‑ can everybody hear me okay? Is it working okay? All right... we have a lot of babies. Almost 400,000 babies, which would translate to 1200 babies with hearing loss a year. One of the biggest problems was, we weren't able to provide insurance coverage for children in the middle. Medicaid's handled. All taken care of, but it wasn't taken care of for our regular families. We're number one in a lot of unfortunate things.

The one thing ‑‑ we're the second highest. California has us beat. How did we get started? Some of you know me well enough to know, I get irritated about something so I start to go after it. And... Texas Academy of Audiology does its audiology association within our state. Most states have them. We have a lobbyist, I joined the board so I could get some legislation passed. I wouldn't say I had 100% agreement, but we worked hard to get it going. Right now in Texas, Medicaid covers hearing aids. And cochlear implants, up to age 18. Our department of rehabilitation also provides coverage for hearing aids and cochlear implants after 18, as they're going on to college or starting a new job.

What I did was researched all the bills that currently happened. This was back in 2012 and... we developed a model bill. What this bill finalized and what all it was through the six years, it was, all it was was an insurance bill. It wasn't meant to be anything else. It allowed hearing aids and cochlear implants, it allowed means to afford them. It wasn't an educational bill and wasn't a bill regarding literacy.

It looks better over there, fortunately. You can see how cumbersome it is to put a bill through the process. We started, we had to find a sponsor, we had to get that sponsor to agree and buy‑in. After we got that done, the bill has to be reviewed by the insurance company, so... the insurance, Department of Insurance is the one that does it. We looked at all of our ‑‑ again, it's a big state. We found 31 senators. I assigned and begged audiologists to represent each of those districts to talk to their legislator and work very hard. We have a whole lot more house representatives.

I'm going to tell you why it wasn't our last ‑‑ it was a rodeo that we had to keep riding those horses through. In 2012, what happened was the bill was filed too late. Why? I was new at this. And I was not allowed to get my parents involved. I said, they told me hold back before we do that, hold back before we do that.

And I do know that was a problem. Our grassroots effort was pretty robust. Wasn't utilizing social media like it should be.

In 2014, oh, Texas legislation doesn't it every two years. You can understand their frustration, having to wait to get something done. This was the status of states with hearing aid legislation at the time. You'll see that Texas is in blue. We had, everybody knows about the Affordable Care Act. If you don't, your head's been in the dirt or something. Texas had a plan called Blue Cross Blue Shield. It did cover hearing aids for adults and children, about $1,000 a hearing aids, not great, but it helped us because it established a benchmark in Texas.

When we had the Department of Insurance review it, they said that Texas is known not to like mandates. We're a very conservative state. They don't like to tell anybody what to do. But... since it was already part of the benchmark, we were allowed to enhance it without it actually costing the state a lot of money. Obviously that'll be something they'll look at.

We were warned back then that this could all change. How many years have we heard that the Affordable Care Act will change? We went forward regardless.

Part of the ten essential health benefits, there's been some threat this year, of changes, it's still present. Number seven was rehabilitative services and devices. I grabbed onto devices and said "that's a hearing aid." We really had some support going into the process in Texas. Here we are, 2014/15, they reviewed it. We had an amazing group of parents and I can't stress that enough, my audiologists did their work from their tables and their desks, but I had one or two show up at the capital. It was the parents and the children that made all the difference. I want to stress that as any important part of legislation you do in your state.

We developed a Facebook page, I'm not that savvy, but we had some amazing parents that put together some really wonderful media.

What happened, which was most‑frustrating, we pushed, we pushed, it got to The House floor, it has to be read three times. There was a guy who was being introduced about what a wonderful intern he was and so time was leaving. There was this other intern, I'd like to recognize this intern in our building, it read, I had so many parents so discouraged and defeated and it was really frustrating so... maybe in some respects, it was good. We had two years to have to regroup.

I learned to not listen to those really wise people and to involve my families from the very beginning. Rather than wait until I got my bill filed. We continued to use social media and I think that's underutilized in some centers and places.

The system we use to notify and to text our legislative people, this is what we want you to support, this is what we're believing in, was sort of antiquated, but it was workable. So... I convinced Texas Academy of Audiology to buy some voter voice, you release it every year. It's a robust program that allowed us to do better eblasts, have a huge database so we could notify everybody, I didn't have to worry about which audiologist was in each district. We, we got across the whole state. And anybody who said they were interested, we put them in voter voice so they'd know about it.

The big boo boo that I didn't know we were supposed to do and I'd like to think your lobbyists will tell you this, but I won't go near there. You should always file a bill in both houses, because... we ran out of time in The House, but if we had a bill in the Senate, we could have kept going forward in 2014/15. I didn't know that and you don't always know what you don't know. And we tried but... you know... I'm an audiologist, we have our limitations.

So... don't always know, but this is some things we did. This, it's not there anymore, you're not going to find it, you have to pay for these things, but... this was our website. It had some great stories, great pictures, and... what was her name? Our beautiful redhead? Chelsea Murphy was the one who did this for us. She did a great job. This was the app that we had during the time before we were able to move on to voter voice and... it was great for what it did, but it was limited as well.

This is the amazing family. I think if you look more close, there's only one audiology in the group that showed up for that one. It is what it is, but... it was the parents and families being affected by this.

Here comes 2016/17, I don't like to dwell too much on the negativity of the previous four years. We moved forward and initiated some legislation. This time, we went through what was available again, what was out there. A lot during our campaign in 2014/15, we heard about problems for cochlear implants. Parts weren't getting paid for, batteries weren't getting replaced. You know... these are very expensive devices and they had a warranty, which is fantastic, but after the warranty period, it costs families a tremendous amount of money.

I found one state at the time, I'm not sure if there's more now, but Wisconsin had a bill that passed that included cochlear implants. We didn't write it exactly like that, but I use that as my model. As I say, you don't have to reinvent the wheel there, are states that have built ‑‑ you should always build upon their boo boos. Every state has them. I remember Louisiana forgot to say any insurance company that serves the people in Louisiana and it got interpreted just the insurance companies in Louisiana. I didn't want to make those kinds of mistakes. We built upon that.

You know... it went through because we wouldn't be talking about it if it didn't go through. This is another website, I know this is too busy to look at, but this website talks about all the different bills that are available. This was on the South Carolina website. Another great resource for you, infanthearing.org website. It has great material for advocacy, letters to your representatives.

Now... they didn't all work with us, we were including cochlear implants, but they certainly can be modeled. You're not having to reinvent the wheel.

We had a great robust Facebook page. I don't know how big our numbers were at the end, but it was very busy with comments and sending things back and forth. Sometimes some negativity, but mostly very positive. We try to utilize every social media aspect we could do. Aside I didn't think to put in, Dr. Audra Stewart did an amazing job promoting it in Texas. You can't just do this alone.

South Carolina has some amazing documentation you can download and look at and again, modify. There's a website on the Facebook page, Jennifer. We have let Texas hear, but there's another one, let America hear? Georgia, Texas, a lot of other states have gone there to help each other out to get this done. Let Georgia hear was another resource.

They pretty much suffered the same amount of time as we did, but it went a different way about getting their bill, their governor did it for all the government employees, to see what the cost would be and then produced it for everybody else. We don't want to waste time.

An article, again, too busy, but I wanted just, for you to see it. Talked about why there was such an underutilization of cochlear implants. I wanted to understand more, I'm not a CI mapper, I don't do cochlear implants. And... you know I asked around and all the different cochlear implant manufacturers, learning more about it, we talked to our parents about some of the things, what we did find, there's serious clinical and financial implications for coverage. Medicaid actually covers unilateral implantation, cochlear implants in all 50 states, but there's huge variability for bilateral coverage, I heard today in our Texas meeting, there's a family having trouble getting the second cochlear implant, even though our bill says mono or bilateral fit.

Another big problem that frustrated me as an audiologist, coverage for post operative therapy was varied. Sometimes insurance covered those services, speech pathology services or whatever, the therapy service was needed and... families were having to pay out‑of‑pocket. This is really, really hard. Even if you're ‑‑ I know, medical people who are very educated and make a decent living and it was almost impossible for them to afford some of these kinds of services.

As you can tell, coverage for parts is limited to the warranty and parents paid between $6700 and $9,000 to pay for a processor. It's covered for one loss or how many times is it covered under warranty with cochlear? People were taking them off and letting their kids play because they didn't want to lose them. You lose the point of putting it on them. You could understand the frustration parents were going to, trying to keep it on their child. Little ones to the young, early years.

What did we do different? Well... we started this grassroots effort at la Madeline's in the early summer or late summer. We met with some individuals and we started planning and scheming and we weren't going to let this legislative year pass without getting something accomplished. What's beautiful is when you're limited, you're kind of a left brain person like I am, I'm not artsy, but we have artsy people in our group who knew how to develop beautiful flyers, put together videos, it was just amazing. I just kind of stood back and was awed. I gave them a lot of the facts, they too it and ran with it and did a great job. We developed elevator speeches, things they talk about, when you see that legislator, they're only going to give you a blessed few minutes of their time. You have to get the facts out, you have to talk about the purpose and all the things that are necessary. They developed a beautiful card that we passed around to all of our committee members. You have to convince committee members, because some didn't want to pass. What did my parents do? They wrote them letters and kept bombarding them with letters until they let us get to the committee. Something the committee realized, this is kind of a no‑brainer. It was wonderful the kind of support. We went to change.org. When we started in 2014/15, we started at 3,000. We got up to 5,000, I think 7,000 and by the end of this year, we had 10,000 signatures. Mostly Texas and we could prove it. We had their information.

People supporting our bill, we would provide that to our legislators as well. And I'm getting ‑‑ I mentioned about the voter voice, that was really a good software program. I'm not promoting that program, there's lots out there, but it worked for us. As far as me having to get a fast, last‑minute, oh my gosh, it may not go to committee because someone wants to hold it up for this because they're mad about something, we sent it out and Jennifer can tell you horror stories.

We had our insurance people look at it again, this is important in Texas, we're a conservative state, no significant fiscal impact to the state is anticipated. Every legislator gets a copy of these reports from the people that analyze the bill. That helped us a whole lot as well. It's to the insurance companies.

Obviously... we're going to have objection from them, but... frequently‑asked questions, we had testimony from our Pediatric champion, right over here, who did an amazing job, got the Texas Pediatric Association to support it. They tweaked the wording and she came sick as a dog, twice, she came and... presented to the council. It was important to have that medical component, you may think... why? Because... it's important to have that medical component.

You have to play the game and I hate to say it that way, but you have to play to the legislators, how they want to learn this information.

It helped to have an audiologist, it helped to have doctors, when they started hearing the parents, that's what was amazing.

We also put together a notebook, it's somewhere in my bag. A little folder that we would give to every legislator, whether it was in the house or in the Senate. Whoever was on the committee and it had stories from families who had problems getting cochlear implants covered, hearing aid coverage and pictures. That's important. Let them see the picture of that family that's being impacted. We always identified the person who was in that person's district to make sure they saw the information as well.

We were still okay with the ACA and essential health benefits. That was still there. We continued to have our website presence. This was voter voice again, this is what we use. I want you to see. It's a front and back page. This gave little short snippets. What was the purpose? Why is it a problem? In our state and across the United States? How many states have passed legislation? Texas doesn't like to look like we're behind the times that. Impacted it too? States are doing it? Oh... how embarrassing, Texas isn't doing it. What was a legislation, what it was not. What does the bill cover? We had to sacrifice some things. There's always a give and take in any situation. I'll talk about that in a second. This is the cool little card that my artsy fartsy people know how to do.

What was neat about it, that's your elevative card right there. We do it, hand it to them ‑‑ it's simple and easy. They don't have time to look at anything you're giving them, but if you give them something short and sweet with gorgeous pictures of babies, it makes a difference.

The difference, that year, we started, it was filed December 5th. Now... we don't have ‑‑ there's a window to file. And you can't do it early in the fall. We did get it filed very early. Notice... it didn't get out of The House until April. We only had a few days to get that passed through The House, to be pushed through. It did get through. Went over to the Senate. We have to meet with the Senate again. We had some opposition from some senators who didn't really want us to even be heard at committee. Our parents did the job. They don't care what I think. They think it's self‑serving, even though it wasn't. They loved hearing from our parents. What was really cool and I think Jennifer's going to address this too. When we all showed up and these parents all showed up at an ungodly hour. We had to get there at 8:00 or 8:30 in the morning. We needed an interpreter. They don't want to pay the interpreter the whole day, I'm sorry, interpreters, they were willing to put us at the very beginning. We had all these families and these kids and I'm just going to say, some things will drop from heaven. We had a judge who had four kids with cochlear implants and she was going around schmoozing with all the people, talking to them and everything like that and her daughter sang Jesus Loves Me. What do you do? Her deaf daughter sang Jesus Loves Me. One of the senators on the committee had a niece that was profoundly deaf and had hearing aids. She married another gentleman and she got a cochlear implant and he got one because they wanted to give their child a cochlear implant. He wanted to see what it was like. They came to testify. It was just amazing and Senator Cokehurst almost cried supporting this. Things fell into place. They don't care what I think. They care what the parents think, in particular, if they're in their region.

We had some opposition, I don't like to dwell too much on the negative. I think I did a lot then, but now I don't. I don't like to dwell on the negative. Things we ‑‑ we expected opposition from the insurance companies. I think they came to The House, but they didn't do anything in the Senate, they knew it was a no‑brainer, they were embarrassing, don't give hearing aids, one of the benchmark‑provided hearing aids.

We had trouble from Texas Association of the Deaf, didn't understand, it wasn't an insurance bill, we worked that out, we had conversations, we talked, we discussed, it worked out okay. They didn't want it to be a mandate. One of the big problems that happened and I, I almost had a meltdown. Is this what we did with the private businesses, we started giving every business to show us their logo. This business wants it, why doesn't your business association want it? You know... kind of quietly trying to shame them without being that way.

But... what happened? Which is when my meltdown came. Is... the representative took out a section of the bill that said it would be covered regardless of deductibles. Well... when the old days, maybe deductible was $500. It's not anymore. It could be $3,000 or $6,000 for a family to afford insurance coverage.

He took that out and I didn't understand why, but we won't go into all that horrible experience. What we did, rather than just giving up... we started thinking, what can you do? So... on the ride to Austin, my sister was driving, I'm telling these stories, because it's though little things that are magical. I'm reading every bill that was passed, what was different about theirs that made it work? Something came to mind called durable medical.

Some things are covered. Wheelchairs are covered but you never pay the whole price. Hearing aids are considered durable medical. We're running out of time, I didn't know it was that fast ‑‑ we got delayed. I'm not going. What happened, we called it durable medical and it'd be covered and a deductible wouldn't go beyond that. Is this where it is now, I'm going to let her talk in two seconds. I'm sorry that we had a little delay with the technical ‑‑  
 >> We may have a break after this, so if anybody wants to stick around for five minutes or so, we can. My name is Jennifer Peterson, a parent of a child. I work with Hands & Voices, have for five or six years. I met Karen at an EHDI meeting in 2015, sitting at a Texas stakeholders meeting. Somebody asked if we knew a specific representative that might help on this legislation and I said "he lives on my street." That started my journey. I have to breeze through this super fast, please come to me afterwards if you have questions, but... what I learned, it's true, one plus one can equal more than two. The more parents that we got, we had this larger and larger impact.

Shared vision is powerful, these parent stories that we have, in fact, my personal story, we found to be very powerful in working with those. We had private insurance, we just assumed when we found out my son had a hearing loss that our insurance was going to cover that. We were completely shocked when he didn't and then we went through the appeal process three times, still got denied. We knew that paying out‑of‑pocket.

I, like Karen, said to myself "that's wrong." Some day, some day... and here we are. Right? Those stories, not only motivate people to be parent leaders and to be engaged, but... it's just that vision of coming together, knowing what you want to do.

The other thing we learned, these networks bring connections like she's mentioned before. We had people in our group, we had a parent from Hands & Voices who happened to work for a major insurance carrier. She had information on what it would cost for an insurance plan to increase to have this coverage. All we started doing was spreading the word and everybody started surfaces that we needed. The judges, the old high school friends I had that worked in the governor's office. I mean... just so many connections. Utilize those. That's a bit about my story, the one on the left is hard of hearing. I was dragging him to testimonies and committee meetings. This boy has known about the legislative process since he was 8 now, 7 or 8. This is our team of parents, the three of us on the far right. Really the core of this group.

And again, we all brought different skills. The mom on the left was the web guru, the one in the middle was the media guru. She got coverage on TV and... radio broadcasts and then I was one of the pound the pavement people. I lived in Austin. I knew nothing about legislative efforts before I started this by the way. It was all learn as you go. This is what I learned and created a roadmap in my mind. Identify your parent leaders. We are out there, we are people that are passionate and ready to help, but... the thing that most groups lack is organization. And so... you do need a few, two or three people that work with you, collaboratively, that can help find out what are your strengths, what are my strengths and divide those up?

A lot is building coalitions, working with your associations like TAA, Texas Association for ‑‑ sorry, Texas Academy of Audiologists. Parents, lobbyists, legislators, it takes all those people working together. Engage with others to change policy. And... again, back to creating that plan, you have to have a plan. There's a saying in Texas and maybe it's used everywhere but there's two things you don't want to see being made. Policy and sausage. And this is true. We learned this through our process. There were people blocking our bill, wanted to block our bill because of favors that needed ‑‑ you know... it just ‑‑ every time we crossed a hurdle, we found a new one. Literally, every single time. Every minute we were like "it's going to get killed, but let's keep going."

In the weeds, a recap of what we did. Social media, we did a lot of identifying who might want to oppose our bill. What zip codes could we use for people to sign our petition? We e‑mailed parents, family members, friends, professionals, we did this at every step. Every time there was a committee meeting, every time something new happened, people were getting blasted. Our personal friends got sick of hearing about this on social media, I promise you. Facebook and Twitter, we used their website. The thing we didn't talk about too much earlier, the websites had very specific information, so... if you were somebody who didn't know what to do, but you wanted to help there, were scripts, sample e‑mails. This is what you send, just plug and play your person's name. There were how do you even find out who your legislator is? I didn't know when I started. I don't know who my rep is. It wasn't part of my world prior to that. So... what else did we do? Big media pushes, very well‑timed media pushes before every big step. Before the insurance committee met, we'd try to get publicity or before you know... that committee met, we'd push on social media again for everybody to make calls. The marketing portion, we had T‑shirts printed up that we wore and stood outside before the vote happened on the floor. We all wore our shirts and passed out those beautiful fliers with our kids pictures on them. We put a face with the issue. It was not just words.

So... what we learned... this was a really big piece too. You can find really passionate parents that unless they are savvy and good communicators and know what those legislators want to hear, you can literally shoot yourselves in the foot here. So... we picked, in a way, we hand‑picked people who brought different perspectives. So... we needed somebody who had you know... gone through something like I have. We needed somebody with CI experience, we needed you know... a family that used you know, different modes of communications. We needed to show well‑rounded pictures of this particular policy. And why it was important. We also tried to speak their language. We knew they didn't like mandates. So... every time we talked to a legislator, we talked about why this wasn't similar to other mandates they might reject or we harped on the fact there was no fiscal impact to the state, other than the fact that if these children who wanted this intervention didn't get it, then we're talking special education class, which does affect those constituents in their districts. Even if this wasn't a personal issue to them.

Knowing those talking points, and really using those. We had to know the process of the filing dates, things like that. We learned to start early and again, in Texas, at least, it takes generally two to three sessions to get something passed, which is about six years. Don't give up hope. Know the process and use your network, understand the opposing view points, if you don't understand why they're going to oppose your bill and you can't talk to that intelligently, then you probably don't have a chance. This is a compassion‑type bill, but we weren't going to win on passion alone. We had to have legitimate reasons for this. That spoke to them, not just to us.

Get involved. This is what I tell other parents. Get involved even when you don't know what to do. When I was sitting in that meeting with Karen in 2015. My heart started racing. I knew I was about to get involved with something I knew nothing about. But it felt wrong not to. Encourage parents there, are so many ways to get involved, they don't have to be the person pounding the pavement at the capital or whatever, they can be behind the scenes working the wept or the voter voice or whatever. So... that's really a brief overview and it really was a rewarding process and I think any parents who get involved will find it to be the same. So... I don't know, we're out of time, probably. We have a short PSA created by one of our parents used in media outlets, I think it's about four minutes. We can play it, you can stay or go or whatever. Hopefully ‑‑ [no sound].

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