## Have you Heard? A Listening Project Episode #14 – ADA 31<sup>st</sup> Anniversary Hosts: Alle Rhames & Jamie Machotka

(0:01) Alle: Hello and welcome to "Have you Heard? A Listening Project." On this podcast we're going to share tips, stories and practical advice to help people who experience hearing loss stay connected. If you or a loved one have hearing loss or if you know anyone with hearing loss this podcast is definitely for you. So, today we're going to celebrate the 31st anniversary of the Americans with Disabilities Act, yeah, and its positive impact on people with hearing loss especially as it pertains to available technology. We're excited to have you join us and I'm Alle, I'm one of your hosts and today. I'm also joined by Jamie, hi Jamie (Jamie...hi). We both work together at OEI as hearing health advocates.

(0:44) Jamie: Well, hi everybody, it's so good to be back and obviously very exciting to talk about the Americans with Disabilities Act since it speaks directly to our line of work.

(0:55) Alle: I know. I was really excited to talk about it because I feel like it's very near and dear to my heart. Oh, I'm so glad to have you here with me, I think because we go so far back Jamie but we can discuss this fascinating topic together, because we do go so far back and because it plays a huge role in all of the work we do to help people with hearing loss every day. So, before we dive into the ADA, Americans with Disabilities Act, I just wanted to talk a little bit about the history of legislation for people with disabilities and let's go back, let's start in the 1970's where we had the Rehab Act of 1973. This was the first time that we actually had federal protections for individuals with disabilities and it protected civil rights for people who had disabilities and it made sure that they weren't excluded from or excluded from participation and/or denied the benefits and the participation in their community, that's so cool. Then, let's flash forward to the 80's, we began seeing access using the telephone in our line of work with the Telecommunications Act for the Disabled and which that was the first time that we actually saw telephones being made available for use in public spaces for people with hearing loss, isn't that great?

(2:10) Jamie: Yeah, you know what? I remember, I remember when you would see a TTY along (Alle...right) with payphone (Alle...yes) in a public space like and airport for example. And for people who don't know, a TTY is a special device that lets people who are deaf, hard of hearing, or have a speech issue use the telephone to communicate, and it's a phone that they type on and they can type messages back and forth if each person has a TTY and they do that

instead of talking and hearing sound but you can also, you can also use a TTY, you know, like if you're someone who's is deaf or hard of hearing you've able to use that and call somebody who doesn't have a TTY and there's a relay service that helps with that it's called the Telecommunications Relay Service so in that case there's a special operator who would type up what the other person without the TTY is saying and then you've receive it on you TTY and if you're the person using the TTY you would type what you want to say and the operator would read it aloud to the other person that you've called.

(3:20) Alle: That's so cool. I think it's such a great invention. I mean obviously and it's a precursor to more advanced technologies which are actually available now.

(3:28) Jamie: Definitely, but let's talk about the reality of having hearing loss and why TTYs and the technology that followed was so important to some people (Alle...okay). Most people who have good hearing don't even consider what it's like for folks who have trouble hearing over the phone. I actually had a friend whose parents both had severe hearing loss, and she tells me fascinating stories about being a young child, and I mean like 5 or 6 years old, and she had to make phone calls for her parents. This was before there were TTY's, there was nothing available to them. Can you imagine being 5 years old and having to make phone calls for your parents? (Alle...no, no) You know like I'm thinking I, calling a hardware store and you have to ask them, do you have a certain size screw or bolt in stock? And then or making, like a doctor's appointment for them? I just, I think about how that would go, and what if I were the person that was answering the phone on the other end? Like if I were the person at the hardware store taking a call from a 5 year old asking about screws and bolts and I would think, I probably think it was a prank call, wouldn't't you?

(4:31) Alle: I definitely would think it was a prank call. I mean a 5 year old that's, that's amazing. And I can't imagine what it must have been like for those kids so little. So anyway, going back to our history lesson, TTYs became more accessible in the early 80s and then one of the things that's been really pivotal in the hearing loss community was in 1988, so this is about pre-ADA by 2 years, but we actually saw something called "Deaf President Now" which was a movement at Gallaudet University where the deaf and hard of hearing students there were actually making a statement that they wanted to have a deaf president of the university. And that particular protest actually got a bit of coverage not just nationally but internationally, isn't that cool, and it was really this first time that community was being seen on a national level and on a global level advocating for their rights and wanting to be seen as having full participation and having the ability to sort of self-govern themselves even at their own university.

- (5:30) Jamie: Right, and that was a great example of how the hearing loss community was able to vocalize how they were so marginalized for so long. And these movements helped springboard the future legislation as well as even the outreach work that you and I and our whole team do today (Alle...yeah) I don't even think there was outreach work, you know, to reach people who were hard of hearing to the level we do it today, you know? (Alle...no I know) It feels like it just wasn't talked about.
- (5:56) Alle: Right. I definitely think you're right, and I think also, you know, to see the expansion of the outreach and resources for other people who have disabilities, not just people with hearing loss it's growing, advocating for that. But again, you know, getting back to our timeline, we then saw the passage of the Americans with Disabilities Act in 1990 signed by President George HW Bush, and that was a super pivotal moment for all people with disabilities.
- (6:24) Jamie: Huge deal! But even today, people I come across, people don't really know what this thing is the Americans with Disabilities Act and as you guys have heard us, we're referring to it as the "ADA" that's what people do sometimes call it. It's a big deal because it is a comprehensive piece of basically civil rights legislation and it prohibits discrimination and it guarantees that people with disabilities have the same opportunities as everyone else, you know, to participate in mainstream American life (Alle...right). And that can be anything from, you know, employment opportunities, how you go about purchasing things, participating in state and local government.
- (7:05) Alle: Or going to the theater, going to school, I mean, it really affects so many aspects of everyday life when you start to think about it. I think that sometimes a lot of us see these accommodations around, but we don't really realize what they're there for, or that they're there because of the ADA and that because if you don't need it, you don't even really notice it. So, like I've seen the signs at some of the movie theaters that reference the assistive listening devices, have you seen those?
- (7:31) Jamie: Yeah, I have seen those at live theaters too and I've been to live theater performances where they've had sign language interpreters interpreting, you know, the entire show.
- (7:42) Alle: Right, oh that's so cool. There are so many things that fall under the ADA. It actually has 5 "titles," or sections, did you know that? That's a lot of sections (Jamie...I don't know if I did know that) Yeah, I don't think I did either until recently but, so like Title 1 for example, that deals with employment and it's for folks, you know, if you're on the job and you need something in order to do your job, you need something called a reasonable accommodations. There's this

story that I actually read about a blind gentleman who tried to approach engineers at some of the larger computer companies before the ADA was passed — he just wanted help, you know, to create software for the blind, and he was turned down flat and he was told there's no money in it. But fast forward to post-ADA, when it became required to provide reasonable accommodations. This man is now a successful musician and a composer and it's all because of advancements in technology that eventually were provided, so cool.

(8:40) Jamie: Yeah and I know that reasonable accommodations, I mean they can be any number of different things including having a phone that's amplified or captioned, it could be having an interpreter for meetings for our deaf and hard of hearing folks. But it could also be things like being able to have access to a braille reader, so you know, that you can, use your computer more effectively and stay connected with your colleagues. So, there's lots of different ways that it can show up in a workplace and I enjoy the fact that part of what we do is make the world more accessible and in lots of different ways including in the work world.

(9:16) Alle: Right. OK, let's talk about Title 2 — Title 2 of the ADA act and that one prohibits discrimination against people with disabilities in programs and activities and services of public entities. So, like public transportation — it has to be accessible. So, now we have elevators, we have ramps, we have captioned announcement on screens, and we have audible announcements. We have those little bumps, I guess they're big bumps really, on the sidewalks (Jamie... yeah) to indicate a street coming up and audible indicators for crosswalks, I always hear those. So, if you ever go to Europe or other parts of the world, you will notice that they don't have things like that — and it's really hard for people with disabilities to get around. Really, it's all thanks to the ADA that Americans have these things.

(10:01) Jamie: Right. I met a gentleman once who was from Germany and he talked about how when he lived in Germany there was a store he came across that was selling wheelchairs, but the store was at the top a flight of steep stairs (Alle...oh my gosh) and he thought "You know, how are people going to get up to this store with all these stairs in front of it?" and he thought that was just so bizarre (Alle...yeah), I mean, I do too (Alle...me too) Let me help get through these other titles. So, Title 3, that prohibits discrimination against people in restaurants or golf courses or retail places like theaters, it's why we see accessible bathrooms, for example elevators that have brail on the buttons, things like that.

(10:45) Alle: So interesting. And then there is Title 4, our personal favorite! So this one deals with telecommunications and this is key in our business because we represent CapTel captioned telephone, which is a telephone that displays

word for word what the caller is saying. So that people who can't hear the words can actually read them on the screen, it's so wonderful! People are always asking us why we're able to get it at no cost and it's really all due to Title 4 — it's that people have the right to communicate over the telephone and to have equal access to the telephone, which means federally funded services need to be available.

(11:24) Jamie: So we really like Title 4 because it's what allows us to help all the people with hearing loss get CapTel phones.

(11:32) Alle: Right, right, and as you know Title 4 includes not just our captioned phones but it incorporates other types of what we call traditional relay, like the TTY that we were discussing earlier.

(11:43) Jamie: Yes, that's right, and Alle, let's hone in a bit on all the different technologies that are now available for folks with hearing loss, since that's our specialty (Alle...let's do it) It would be helpful if you could just name specifically some other types of auxiliary aids, I guess we'll call them? For people with hearing loss just to give an overview for maybe people who are listening that have no idea what those are.

(12:05) Alle: Well, sure. I think that auxiliary aid is probably the language of the law, but you know other devices or technology or things that people have figured out to use that will support people with hearing loss — there are so many. Let's see, like sign language, sign language interpreters, which you've probably seen on TV for anything and everything these days. There's also note takers, who are often seen in school settings providing notes for people who are deaf or hard of hearing. We have amplified handsets, which is another way for people who just need some amplification on the phone in order to be able to hear what's being said and to be able to effectively have access. Assistive listening devices, Jamie you touched on this a little bit about, like, when you go to the movie theater, sometimes you'll get an assistive listening device so it'll be louder. I know that my grandparents would do that. Sometimes you might also get access to special captions. Telephones that are compatible with hearing aids — every person who wears hearing aids has had that experience of having the terrible feedback on the telephone, so the ones that are compatible with the hearing aids are really important.

(13:11) Jamie: Yeah, and that feedback, that's the worst (Alle...yeah) for those of you listening. If you all don't know, it, it is the squeal of the century that you, I feel like nobody can miss. So, if you hear that squeal that you're getting, that's exactly the kind of terrible feedback Alle is referring to.

- (13:28) Alle: It's the worst! Yeah, also open and closed captioning. So, we're all familiar with captions on our television typically you can just turn them on or off. Some places have what's called open captions which means captions are available at all times on the screen. There's also real time captioning which is what you will see on a news broadcast. Then, there's also CART reporters and they're providing captions on the side.
- (13:57) Jamie: And for those of you that don't know, CART stands for computer assisted real time transcription, which is just a fancy way of saying somebody who uses a special device to provide captions. Typically it looks like that machine that you see court reporters use.
- (14:13) Alle: Right. And right now there's also speech to text transcription. And then of course what we all love now voice text and video, I love it, and that's based, based ways of communicating with the world.
- (14:27) Jamie: And 20 to 30 years ago we wouldn't have imagined that we would be walking around with phones in our pockets that we could text on or send video on or call people on and yet that's what some of us are using these days. And all of those devices can support people with hearing loss and I'm sure there are others, but Alle I think you've covered a lot of them.
- (14:47) Alle: It really is amazing to think of all the technological advances that are integral to making the world more accessible to people.
- (14:55) Jamie: Absolutely. And now we're going to take a quick break to hear a word from our sponsors.
- \*\*\* Commercial My mom and I used to talk on the phone everyday but lately she can't hear me when I call. I have to repeat myself over and over, it's so frustrating but I know it's even more frustrating for mom. Thankfully, we got her a CapTel Captioned Telephone, it's just like the captions you see on TV only for phone calls. Now if she can't hear what I say she can read the captions. Our local CapTel Outreach person took care of everything. It was so easy we're back to talking every day and it means the world to me and to my mom. If someone you know can't hear over the phone we can help you get a CapTel phone at no cost visit oeius.org for details.

(15:49) Alle: And welcome back!

(15:51) Jamie: Well, my favorite part about doing the podcast is actually being able to share with people the real stories. But before I do that, I know we

mentioned that there are five Titles to the ADA, and I don't want to forget about the last one. Title 5 actually pertains to legalities surrounding the ADA and how to enforce the provisions. It's definitely necessary, but not that exciting to talk about, so I think I'll just jump into a story that pertains to the work we do. So, as we mentioned, Alle and I do outreach on behalf of the CapTel captioned telephone. We introduce it to people, and for those who need it they're able to get it at no cost and that's all possible because of the ADA, the Americans with Disabilities Act. This is one of my favorite personal stories – So, I have a client who developed hearing loss during her childhood. So she grew up, she went to school she was able to talk and then she made her way through school her hearing kept diminishing and diminishing and eventually she wasn't able to communicate on a telephone at all. And unfortunately, she didn't know sign language so she was one of these people that was just left in the dark and she was only able to communicate with people either in person or writing letters and even when she was in person she was lip reading, or people were having to write notes to her on paper.

(17:09) Alle: Yeah, and it's just so hard when you're not having that complete and full access to talking to anybody in your environment or whoever you want to talk to. We talked to lots of people who have progressive hearing loss a lot like your client. Anyway, you were saying, tell us about how she's using the phone now. I'm assuming she's using the phone now somehow, right?

(17:29) Jamie: Yes, luckily I'm, I'm not telling a sad story it gets better right now (Alle...good). So, we fast forward now we have the Americans with Disabilities Act which means we have these other supportive services and devices available to people. And what it started with was TTYs that we talked about. So my client, she was super excited when she got to start using a TTY because at least she could call people. The difficulty though, was that she wasn't able to speak with her own voice, she was always having to type what she wanted to say and then an operator would read it aloud to the person she called. So it was better than nothing but it wasn't ideal (Alle...right) and then CapTel became available and she started using that and for the first time she was able to start calling her family members directly. And all of them, not one person didn't cry, they all cried because it had been so long since they actually heard her voice on a phone (Alle...right). And, you know, I think about my own life, I have family that lives far away in another state and I can't imagine especially during the pandemic if I couldn't call my mom and talk to her on the phone like if she couldn't hear my voice at all (Alle...yeah) yeah, that would be so hard. So, anyway, this, this client really made me understand to a deeper degree why the work that we do is so important. I mean it literally changed her life, so you know, now she is still in touch with me and she's really appreciative but I just like that we can help somebody like that and it makes me grateful to the ADA in that respect because it may not influence my communication directly but it's people all around me, people's families. I mean calling the doctor, calling the bank, a lot of us text, but not everybody has the dexterity to text (Alle...right) and not everyone is open to texting, you know, like I have a 2 year old and when I want to make an appointment with his pediatrician, I don't get to text them (Alle...right) I have to call. And also there's this issue with inflection, right, that you really can't get with texting, and it could lead to a misunderstanding. This has definitely happened to me on many occasions and gotten me into some hot water where I'm trying to say one thing but it's read as another.

(19:53) Alle: Yeah, and then you're spending all this time looking for the right emoji just to convey what your mood is, we've all been there. So there are still things you really do need a telephone for! Now, since you got to tell a great story I have to share one my favorites and I will never forget this one. It was many years ago but it was one of the first ones that really hit me. So I was setting up a telephone for an elderly couple mainly for the husband who had never used the telephone in the last, I think it was 25 years because he couldn't hear on the phone, he couldn't understand and he got too frustrated. So he literally hadn't used the telephone in that 25 years. So he was very resistant to getting a captioned phone which a lot of people can be very resistant to new things. But his wife was bringing it in so that they could use it together even though she really didn't need it as much. Anyway, when I came to set the phone up for him, he was in the corner in a wheel chair despondent didn't really, you know, pay much attention to me which is fine and I set the phone up with his wife. Once it was ready to go, we had his son who lives on the other side of the country on the east coast, call and the ringer because it's so loud, the ringer can go up I believe to 90 decibels which is really, really loud. He heard the ringer, he actually heard the ringer and he looked up and I think that was the first moment that he was like, wait maybe this is something I can actually use. So we brought him over to the telephone and he said "hello" and he also started balling, balling crying because he could sort of hear, you know, he couldn't actually make out the whole conversation but he had the captions to be able to read the conversation and he could also slightly hear his son's voice. I'll never forget that, that was just unbelievable in terms of, you know, the work that I do, it made me feel good, they were happy it just was a full circle type of situation.

(21:51) Jamie: Yeah, I mean that's pretty much my favorite part of our job. Just how we get to help people, just like that (Alle...right) and I think choosing to talk about the Americans with Disabilities Act today was great because it's just so important for people with disabilities, and people without, to know what's available out there, and why we have some of the things that we have. You might be someone listening to our podcast who didn't know these things existed. You might know somebody who need some resources or some help so we just

wanted to give the historical overview with some real stories of clients, you know people that have been impacted, because there's just too many people who don't even know what the ADA is. I have come across so many of them and they're like, oh yeah, yeah, yeah the Americans with Disabilities Act, but if I actually asked them what that means or what it covers in like in everyday life, they, they have no idea (Alle...right). They're like, oh okay, yeah that's for you know, disabled people and I put quotes around that, and it's like, no it's, you know when you get older when all of us get older we maybe in wheelchairs, we may need to walk with a cane (Alle...yeah), we might need to make sure that we've got a curb to step onto or a flat surface for the wheelchair to roll up and, you know that could be me that could be you someday it could be any of us.

(23:14) Alle: Jamie, I'll walk with next to you in a cane any day. Yeah, I was watching a TED Talk presentation by a gentleman whose, he's a deaf gentleman who works for Amazon and he works on Universal Designs so he looks at how to create things that are available to anybody. He said this really wonderful thing, where he said disability drives innovation which I thought was such a wonderful point. I'm just going to repeat that, disability drives innovation. It really does and I just love quoting him now, his name is Michael Nesmith and it was a TED Talk in Boulder. He also said the existence of disability really forces us to come up with new solutions and all of us at some point in our lives are going to have some kind of disability be at physical, a cognitive or just a temporary, you know like a broken arm and you know you can't turn a doorknob or if you're going through some sort of medical treatment and you've got some temporary hearing loss, our devices might be able to support them. So, you know, at some point all of us are going to experience some sort of disability and it's just okay to accept that and the ADA just offers that opportunity for all of us to have access and I think that's what's so important about it. It's not just this particular group of people, it's about all of us.

(24:30) Jamie: I couldn't agree more. Well, I think that's all we have time for today (Alle...ohh), if you're someone, oh you're bummed, I'm bummed too but (Alle...this has been so fun and interesting) yes, it has and so if you're someone who is looking for more information, visit our website — it's oeius.org, we have so many resources that can educate and help people with hearing loss. So, that's O-E-I-U-S dot org. Alle, it was a pleasure being with you today.

Alle: Ahh, it was great working with you today, Jamie. I'm really excited that we got to do this podcast on the Americans with Disabilities Act.

Jamie: Me too. And don't forget to join us next time when we're going to talk about some of the best vacation spots and travel tips for people with hearing loss. In the meantime don't forget to subscribe to this podcast so you don't miss out. I'm Jamie (and I'm Alle) and we want to thank all of you for joining us today

on the Have you Heard podcast and remember to stay safe and stay connected, bye folks! Bye!

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