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Advancing Access to Hearing Healthcare: Yes, You Can Advocate for Positive Change!

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Presenters: Donna L. Sorkin, MA; Nichole Westin

Thank you very much, everyone, for being with us on this course on advancing access to hearing health care. Yes, you can advocate for change. I am being joined today by Nichole Westin, who is our governmental affairs manager at ACI Alliance. She has been with us for three years, but prior to that she was involved in advocacy at the state and local and nonprofit level for about 20 years, so we are really thrilled to have the chance to share information with you. Here are our presenter disclosures. And just to give you a sense of what we are going to cover today, we are going to talk a bit about what advocacy is and who can advocate the process and tools in hearing health care, Federal and state regulations.

We are going to tell you a bit about what we are looking at and how we do it as a window into what you might want to do, and some information on case studies, and we will leave time for questions at the end. So you may wonder why there is another organization in hearing health care because there is already so many general organizations in the field. We are focused on cochlear implantation, and our members are drawn from across the care continuum. We focus just entirely on Cochlear Implants, and we have a website that's designed for those who are both in and outside of CI because as part of our mission, we really do want to provide information for the larger world.

We are highly collaborative with other organizations, including audiology on-line, and we welcome your involvement if you are not involved yet in ACI Alliance. We would love to have you be part of our network and have you work with us. So this is our mission statement. It hasn't changed since the organization was started in 2012. It is to advance access to the gift of hearing provided by cochlear implantation through research advocacy and research. So advocacy is in our mission statement, which is kind of unusual for a nonprofit organization to recognize that right at the front end. We look at factors that contribute to under-utilization of Cochlear Implants, and we know in the United States, only between 5% and 10% of those who can benefit, actually, have Cochlear Implants.

Our objective today is very specific, to share information, to help patients, and professionals engage in advocacy and to do that effectively. These are our learning outcomes that we have provided earlier. And you might want to start by wondering what is advocacy and who can be an effective advocate? Advocacy is an activity by an individual or a group that aims to influence decisions within political economic or social institutions, and we can use publications. We can use research to educate Government officials and the public at-large, and when we do that -- we do that at ACI Alliance, and many activities qualify as advocacy. It can include media campaigns, public speaking visits to legislators or their staff and lobbying, which is typically viewed as an activity that is for one specific issue or proposal.

It's important because it can help us bring about positive change in people's lives, and it helps people feel empowered if we allow them to advocate for themselves or for others on an important issue. It's also an opportunity for those of you who are professionals to contribute your expertise and your experience to this process. I often find that professionals feel uneasy about getting involved in advocacy because it's outside of their comfort zone is, but at the same time, as professionals and experts, you are very incredible. We take professionals in to meet with Government officials and others, it's always very convincing and very, very effective in terms of what we are trying to do. Our Government encourages self advocacy and encourages individuals and groups to advocate, and legislators listen to people.

They listen to special interest groups when the argument is compelling. You need not feel that this is something that you shouldn't be doing. Research on advocacy shows that organizations have a central role in advocating, and they take advantage of rare policy windows, and they can be very effective when they do that. For example, right now with Covid, this has created a policy window for us for tele-health, which is something that many of us have advocated for in the past, but we did not have the support for it. Given what happened with Covid, we have been able to get insurance

coverage for this time frame, and we are trying to extend that past the health emergency, and often these policy windows are short-lived, and you have to take advantage of them while you can.

We have really tried to do that. So research on advocacy also shows that messages need to frame and respond to the political environment and be aware of those, and by understanding the key steps, advocates are better equipped to effect public policy in a positive way, and we have given you resources there that you can go back and look at. By the way, everyone is doing it. If you look at our hearing health care field, you can see that a lot of organizations are involved in advocacy, and organizations that we like to look at that do this really well is the Michael J. Fox foundation and the American Medical Association. So I want to find out a bit about who you are.

We are going to give you a short poll right now. We are going to put that up. And ask you to take a minute and fill that out. hello, there it is. Go ahead and tell us a little bit about yourself. Are you a hearing health care professional? And if you could just take off who you are and do you work with -- do you work with patients or Cochlear Implants or hearing aids or other. Are you a CI recipient or family member, and have you participated in advocacy before? We are encouraging you as participants to fill that out, if you can. I will just give you another few minutes, and I am not seeing anybody voting.

So I think that we will just continue on. Why don't you take it off, and we will move on. The point really is -- oh, here it is. People did vote. I just couldn't see it. So this is great. 73% of you are audiologists. 5% are hearing aid dispensers. And other, 23%. And we asked if you worked with patients with Cochlear Implants, and 41% of you said that you did. Hearing aids, 45%. And the other is 14%. Are you a CI recipient or a family member? And 9% are. 91% said no. And have you participated in advocacy before? This is great. It's 50-50, so half of you have and half of you have not. So this course

really is for everybody. It helps those of you that haven't done it get more effective and help those who have not to get involved.

So, these are some of our great advocates that came with us. When we went to the hill in 2018, and we just took a whole group of vocation who came in for the annual meeting in Washington. It was really a wonderful opportunity for them to demonstrate their knowledge and passion and their desire to improve services for patients. We had consumers. We had parents. And we had hearing health professionals who were there with us. Everybody was very anxious to learn and to collaborate. Those visits, of course, are very important, when you can make them. We will start doing them again after Covid. It's also important to use email and make phone calls and tweet and paper is out.

No one uses paper any more. This was one of the visits that we made that day to Representative Susan Brooks from Indiana. And we had most of those people from Indiana. That's Susan Brooks, and the person to the right is a constituent that knew her, and she is a parent of a grown child with a Cochlear Implant. I just wanted to review the complexity of Cochlear Implant complexity because it is very complex. This is a busy slide, but it helps you see the different ways and different topics that we have to look at we need to think about things in terms of laws and regulations. So we pass laws. Then, administrative agencies charged with regulations. And we passed the hearing aid bill, and the regulations are to be put out by the FTI.

They haven't been put out yet, and it's very important that be done carefully. If you move to the right there, advocates have various perspectives. They are professionals like most of you on this call -- but also they are parents and consumers and others, so all those perspectives are important to include. The candidacy for adults and children for Cochlear Implants is different, as you may know. So we have to approach that with that specific audience in mind. And insurance types, also, make a difference, and we are going to talk more about that. We advocate differently for different types of

insurance, and our objectives are often different. All of that makes it interesting and challenging, and it's important to our efforts in terms of directing ourselves appropriately.

So I am going to turn it over at this point to Nichole Westin, my colleague, who is going to cover some other issues.

>> Hello, everybody, I am so excited to join you all today. So as part of my responsibilities at the ACI Alliance is that I work with our various advocacy networks. Our state champions are -- were founded the same year as the ACI Alliance. They are our core group of people who work on our various issues. We currently have over 120 champions from 43 states. Certainly we would always like to grow those, and they come to us from across the continuum of care. There are surgeons, SLPs, audiologists, consumers, and parents. And they are the people who provide us with a background on all of the state and national issues that are impacting CI.

Very often they are the ones who come to us to let us know that there is a situation that is percolating at a state level. They also let us know if they are seeing issues that are growing due to a particular new policy or ways that we can maybe impact things at the national level, so we certainly do rely on them quite a bit. Last year, and it's nice to finally say last year, we launched our brand new CI consumer advocacy network. We are very excited about this, as it is a new venture for us, and it is aimed at enhancing and enlarging our efforts with first hand knowledge from our CI recipients and families. We have found that, you know, as vital as the input is from medical professionals it is really the personal stories that can often make the difference and positively impacting decision-makers.

So Donna mentioned earlier how everyone is doing advocacy, but there are often people who wonder why they should do it. But to also to understand why there are people who do not participate in advocacy, the American Nursing Association in 2019

asked all of its members why do you hesitate to advocate? So the top three reasons were, the perceived lack of public speaking skills. They don't understand the political process. And they don't necessarily understand the link between regulations and the process. And we are here to tell you that most organizations have ways to address these issues, and many people have employees, such as myself, who are there to guide you and to assist you and to help you overcome these previous three key topics.

So why advocate? If you are on this, you have either done it or, you know, the polls showed 50% of you have not but you probably are wondering how to go about it. So these are questions that I like people to think about, about why they should become involved such as what are the challenges that you and your colleague are encountering? Whether it's during this Covid experience or before then, and certainly, afterwards. What challenges do you see your patients and others facing, whether it's insurance denials, equipment issues, and the like. And what has worked well? What are things that you all hope could be replicated, whether at the state or the national level? Or have you maybe heard about how a state is doing something different and better?

And how can we implement that in your own state? And how has having a CI or hearing aids or a device improve life for your patients? That is always a general important nugget to frame stories about, and this is the one that I find drives people to become advocates is how can you help those who are coming behind you? How can you not only help yourself but your colleagues and the people going to be doing this work five years down the road, ten years down the road. When advocating, it is incredibly important, especially in the medical field, to use scientific research, supported, of course, by personal stories as these generate the best connection with policy-makers.

From the outset, our mission has combined at the ACI Alliance research advocacy and awareness. And it's very important when you are talking with people to demonstrate

outcomes with this medical intervention. For example, the cost effectiveness study of CI in children, which was first published in JAMA in 2000 has been a study constantly referred to for a variety of reasons, including showing the long-term benefits for insurance companies, which is a business, to cover CI in children. And there is an update on the study under-way, and it will certainly help us all in the future as we continue to advocate for this. Common advocacy tools that reach across all different organizations. I have used them at other previous jobs, and we certainly use all of them at the ACI Alliance.

Advocacy software, which helps to track the legislation. If you are doing both Federal and 50 states, there are a lot of moving pieces, so it's good to have a way to make sure that you are not dropping anything and keep up with what is happening in those areas. These software options also send alerts to people to let them know when there is a vote that's about to happen, to help gather their input, and also to turn around and use those alerts to email officials. These are formulated and programmed to be easy to use and to rapidly respond from anywhere. The position papers and statements are critical to all of this because they form the talking points for an organization on any and every issue that they are interested in.

And looping back to the previous slide, research always is a fundamental part and should be a fundamental part of the development of both those. Advocacy tool kits, this helps to answer some of the questions that people have about why they do not advocate, about how to do it and what to do to help members, such as yourselves, understand the process and how to get started. Coalitions. Donna mentioned earlier that we are very involved in various groups, and the broadest reason to join the coalition is that many voices make light work, and they also grow the grassroots organizations with various people to tap into. And the broader the group, the better, especially if you can reach across various divides.

And social media. This is one that when I started 20 years ago did not exist, and now it is possibly one of the top ways and best advocacy tools that we have in our pocket. So all policy-makers have social media accounts, whether it is members of Congress, Presidents, Vice Presidents, state officials, local officials, your Mayor, everybody has one. Everybody uses them, and they also have staff dedicated to following and responding to messages, especially when it comes from their constituents. There were two -- have been at least two studies, and I am sure that there are more, specifically, focused on Twitter, and the impact it has on reaching policy-makers and the broader context. In 2015 the Annals of Epidemiology recommended targeting the key decision-makers on oversight committees, at both the state and Federal level, an oversight committee is the one that gets the process started when it comes to a bill or legislation.

If you -- if you hear any bills, over the counter mentioned earlier, the key place to start if you have wanted changes to that would be with the various subcommittees that draft the bill and hold the first votes on the bill and the hearings to receive input from the general public. Just last year the Pew Research Institute found that since 2016 a typical member of Congress now tweets twice as often, has nearly three times as many followers, and six times more -- as many tweets on various posts. So this is something that is clearly the best way to reach your members of Congress and your local officials on issues that are important to you. This is one of our favorite things that we like to talk about, and this is an example of how we share something on Facebook, who is Andi Hill, who is in Alabama, and is one of our state champions who we are all incredibly fond of and proud of.

She's a parent advocate, and she shared a story on our Facebook Page, and excuse me, on our website and our magazine which we then shared on our Facebook Page, which tells the story of the journey of her three children with CIs, and the incredible outcomes they have had. When we shared her story on our Facebook Page, with only 13 shares it reached over 5,000 people on Facebook. It also helped with outreach to a

Federal agency on very key and necessary changes to their website. So one simple post made a huge impact. And I am now going to turn this back over to Donna who is going to talk about the laws, regulations, and insurance and dealing with hearing health.

>> Thanks so much, Nichole, and a shout out to Andi Hill, who is on the call today, she is the family that Nichole highlighted on Facebook. So just to give you a little bit of an overview of laws and regulations, and insurance and hearing health, and this is really going to be a 360-degree overview because we don't have time to do anything in detail today. But just to give you a sense of really how this, how this works. Let's see, what I want to go to the next slide. Tech support, could you move me to the next slide? I am not able to move over -- there we go. So just to begin with, a bit of an overview on the concept of disability because this really had to change in our country before we can have some of these laws that are so important to us today.

And this concept of disability now is that services and accommodations should be provided to allow a child or an adult with access. And we cannot discriminate based on disability. The laws in the U.S. now are designed to focus on freedom from discrimination based on disability. Interestingly, I am reading a book right now. It's a biography of Franklin Roosevelt and how different things were in his time in the 1930s when he really was having to hide his disability. He was considered crippled, and that was -- that was a bad word, that was considered something that someone could never expect to become a politician much less the President of the United States, so we had to overcome that perspective in order to pass laws that would allow people to be fully included and accommodated.

And this includes technologies today, such as cell phones and broadcast cable and TV and the fact that we just believe that people are entitled to be included in society. And, of course, one of the landmark laws for children are the educational laws under IDEA. When it was first passed it was called the education for all handicapped children act,

and the name was, of course, changed later, but it was the main Federal program that requires states and local Governments to address the needs of children with disabilities in educational settings, and there is two parts to it that focus on the age of the child and the services are different depending upon the age of the child. But professionals really have a key role in helping families ensure that everything that a child needs is spelled out, and your expertise is really, really key in terms of helping families achieve what they need for their child.

And then the other aspect of educational access is section 504 of the Rehab Act. All entities that receive Federal funds must also offer services that provide access, so it applies to public schools and colleges and universities. Some children who have Cochlear Implants or hearing aids are now performing at grade level, and their categorized as not having an educationally significant hearing loss so may not be eligible for an IEP, but we must still provide services such as an FM system or an interpreter or captioning to help that child have access to programs. That requirement is under section 504 of the Rehab act, as well as the ADA. So with the educational advocacy, we really want to make sure that families are getting what they desire for their child, and that can be challenging.

Families want to do the right thing for their child, but they may be unfamiliar with the process and how to advocate, and sometimes they find themselves on the opposite side of the table from experts who seem to know what's best for their child and feel hesitant about rocking the boat in their child's school. This is, again, is a place where professionals can be very helpful to families in understanding that they do have that right to get what their child needs to excel in school. And other very important laws with the early detection and intervention act, Federal legislation that was designed to ensure that newborns and young children with hearing loss are identified and received the care that they need, and we are now screening 98% of the babies born in the U.S. And they have that hearing screening. It's made a huge difference in terms of being able to identify children at an early age. When I first became involved in this field the

average age of identification of a children with hearing loss was 2.5 years. So by then they had missed all their milestones, and no matter what technology you put on them, it was very difficult for them to catch up. So, we do still have problems remaining. The lost to follow-up issue where we identify a child and then they get lost in the system and also insuring that families are told about the full range of options that they have for their child, and that they can get those options if they wish to have them.

On the general access front, the grand daddy of all the laws, of course, is the ADA. It covers employment, state and local Government, public accommodations and telecommunications. Employers and facilities are required to provide reasonable accommodations. Those are not specifically spelled out so the individual does need to work with their employer or facility to get those. And courts have been quite supportive of people if they are, in fact, asking for reasonable accommodations. There is a specific process for filing complaints. Section 504 is also a place where someone can seek services. I mentioned this earlier under education. So insurance and advocacy are another aspect of what we advocate for, and we are going to talk today about four main types of insurance, Medicare and Medicaid and military/VA and private health insurance, and we work in all of those realms.

We will talk about them briefly in our talk today. Medicare is the first one that we are going to talk about. It does cover cochlear implantation and other hearing devices, but not yet hearing aids for beneficiaries who meet candidacy criteria, including equipment and for Cochlear Implants, upgrades are provided every five years under the Medicare rules. There is an ongoing effort to broaden the candidacy so that Medicare more closely matches the FDA. Right now it's more stringent than the FDA guidelines. Also, traditional Medicare does not cover single sided deafness, and the language on bilateral Cochlear Implants is ambiguous, and is interpreted differently by different CI centers, so depending on where someone goes, they may be able to get a bilateral Cochlear Implant at one center and be declined at another center because Medicare does not pre-authorize.

It leaves the center in a difficult place. At present, hearing aids are not covered. Nichole will talk about that in a minute. There is no mechanism to advocate for different kinds of coverage under Medicare. So it's kind of -- this is what it is, the situation under Medicare. Okay, I am going to turn it back to Nichole at this point. She's going to pick up on the next type of insurance. >> Thank you, Donna. I somehow cannot advance. I don't see the thing. Oh, there it is. Sorry about that, everybody. Technical difficulties on a Wednesday. So again, we are going to do a quick overview of Medicaid. Medicare and Medicaid, of course, were created in the 1965 as part of the great society programs, but they are separate programs, and they operate differently.

The Medicaid is a joint program, which is funded primarily by the Federal Government, but it is run at the state level, so coverage, of course, differs greatly between the separate states, and the state Governments also provide the additional funding for Medicaid, as well. It is health care for persons of all ages, whose income and resources are insufficient to pay for other health care. Children are covered by Medicaid for CI hearing aids and therapy and all of the -- in all of the states, and as I said, adult coverage does differ for hearing health by the different states. Because it is a separate program in each state, you know, the rules are so different that it can be a bit complicated to kind of bear down on it.

Adult coverage varies. Some of them cover hearing aids, and some CIs and some do not. While children are covered in all states, sometimes the candidacy for a CI can differ as well as after-care rules such as therapy sessions. And across the board generally reimbursement is poor, and many of the -- in many of the states for the surgery. However, there is a process to change Medicaid coverage policies in the states, and we have done so, and we will talk about that in a little while. Private health insurance, most of the majority of them do cover Cochlear Implants for all ages. They do typically follow the FDA guidelines. After-care coverage does vary, but most of them do cover durable medical equipment.

There are still significant challenges, especially when it comes to coverage for single-sided deafness. And there are some insurances out there that might cover hearing aids, but there are not many. Advocacy and persistence can be implied to insurers by physicians, beneficiaries, and others to make changes to this. We have seen private insurance companies shift policies, especially when it is -- when it starts with a case that has been denied and there is consistent and persistent pressure applied through medical professionals and their patients. So as we talked about, you know, we have to choose your issues and focus, and for the ACI Alliance that is always the focus and the issue is access to Cochlear Implants. That brings us to the list of issues that we think are going to be popping up and we might be working on in 2021.

These are issues that other groups and organizations out there might be working on, as well, and that we will be partnering with. These are the ones specifically that we are talking about on the ACI Alliance side. Of course, as always, expanding public and private insurance coverage for CIs. We are certainly focused on single-sided deafness. It's probably one of the top questions that we get in general when it comes to insurance coverage. We can, you know, as we mentioned earlier, changes can be made at both the public and private level, especially when we have the research to support it and input from physicians and patients. We will also likely be certainly working on tele-health coverage in the next year.

There are certainly others focused on this, as well. We continue to focus on protecting parent choice, and which is to ensure that parents have access to unbiased information on language options under EHDI. One of the new ones we've been working on is CMV screening. This is the most common cause for non-hereditary hearing loss, and we have supported state what you efforts on screening to quickly identify the infants with CMV. Continuing on, we are looking at possibly IDEA and EHDI funding, and potentially reauthorization in the coming years. They are due for reauthorization at

the Federal level, and as Donna mentioned earlier, they provide most of the legal protections for access to hearing services and education for children with hearing loss.

As always, there are issues with full funding, and there are other organizations that are also working specifically on this. We are looking at expanding access for Veterans as well as information on the fact that the V.A. covers CIs, especially if the hearing loss is related to their service, and we are partnering with Veteran service organizations to share our information and our resources. We also recently collected a wide variety of stories from Veterans on their CI experience, and we have found that to be helpful to share not only with Veterans, but other adults who are looking at obtaining a CI. One of the bigger issues that we worked on last year and will be looking forward to working on in the coming months is the Medicare hearing aid bill.

This is a bill that was passed by the U.S. House of Representatives in December of 2019 and was incorporated into a larger bill that was a part of a larger bill that included vision and dental services, as well. The inclusion of hearing aids, as prosthetics for individuals was for those who are diagnosed with a profound or severe hearing loss. We absolutely support hearing aid coverage, but we did have concerns about the focus on the profound or hearing loss population because many of them would benefit to a greater degree with a CI over a hearing aid. As we mentioned before, CIs are covered by Medicare already. We met with congressional offices asking about language to be included in the bill, and that is referral language in which it would refer patients with a profound or severe hearing loss to be looked at for what type of technology would best serve their own individual needs.

So far, we do believe this is going to come up again in 2021, as I said, but we do think it's probably going to be part of a much larger Medicaid legislation in the future. So we are going to move on to a few case studies that we have worked on through advocacy over the past couple of years. First up is tele-health. So pre-covid there had been expanded interest in tele-health in general. We saw this in rural areas without access to

specialists as well as rural areas where, you know, even just the drive to a general practitioner could be months to make the appointment or the drive was significant to the families. Private insurance companies have allowed tele-health visits in many cases, and some states, such as North Carolina, already had laws mandating the coverage.

So, and what we have found since Covid is that many of the outcomes, when it comes to CI appointments are very similar to in-person services. We recently launched a research that we are funding to document these outcomes in a more formal manner that we will be able to present to support our case to make these current coverages much more permanent. What happened is that with the Covid and the emergency health provision, CMS implemented broad waivers for tele-health and most other insurance companies followed suit, but to make the Medicare flexibility permanent, there has to be legislation passed by Congress. There are many organizations who are ready to move the bill this year, and that would be spearheaded by the AMA, and it is certainly something that we are going to be participating in, as well.

So this is one that we are certainly very proud of. It touches on a few issues that we have covered in this Webinar, and that is the denial of a Medicaid coverage for a single sided deafness in a child who lived in West Virginia. The mother had contacted the U.S. Congressman McKinley, who is the only member of Congress with a CI, and the staff forwarded the details to us to ask for our help. What had happened is that Medicaid denied the single-sided deafness CI multiple times, and there was one final Hail Mary, which would be a hearing before the Board of medical services. We helped them out by providing research on various outcomes of single sided deafness, and the importance of having an ear to be aided for better outcomes, we developed and published a white paper that is located on our website about the importance of aiding an ear.

We also suggested that she contact legal aid for a pro bono attorney for when that hearing took place, which she did to great success because the -- during the -- after the final appeal to the Board of medical services, the denial was overturned, and the surgery went forward with great results for the family. This is something that we are incredibly proud of, but also, shows that Medicaid coverage can be changed with the persistence and her medical clinic was also incredibly key to this, as well as input from the Congressman's office and the ACI Alliance. That leads us to the third case, which is talking about how you can change Medicaid. As I mentioned earlier, most states cover CI in adults.

That number hovers around 60%. We do receive many inquiries on adult coverage from those states that do not currently cover it. In 2018, the adults of Maryland had complained to the disability rights group in Maryland about the lack of coverage, who then in turn contacted us for assistance and expanding coverage there. We provided research on quality of life, the impact on employment and disability coverage, lower health care costs overall, and in the future, and they decided through the regulatory process to change the rules in Maryland, so now they do cover adults in the state, and they also do cover some equipment, as well. We were able to use some of our state champions in Maryland to help provide input on the letters that we drafted, and since then, there have been some adults who have been implanted in the State of Maryland under Medicaid.

We have other clinicians interested in pursuing coverage in their own state policy, some of them were derailed by Covid, obviously, but we hope that we can pick that up in the coming months. And we are seeing some progress already in the State of Washington. So here's some references that we would like to provide. One is, of course, just overall insurance coverage for CI found on our website. Also, as well, the pediatric unilateral hearing loss paper I mentioned for the case that occurred in West Virginia. Donna's piece that she wrote in pediatric audiology, which covers the educational access laws. We do also have numerous other options that are available

on our website, and if there is any other references that you might possibly be interested in, please do contact us, and we would be happy to answer any questions.

So thank you all very much. I think that we can open it up to questions. >> Great.

Thanks so much, guys. I really appreciate the content here and the great work that you are doing. One question that came in, the ACA replacement plan coverage for children's hearing aid is vastly inferior to my state standard Medicaid coverage in terms of provider, providers that are in network, and quality of hearing aids and ALBs covered. I live in a rural area, and now with the replacement ACA plans, I have patients who have to drive up to five hours for children's hearing aid services to be a provider in a major city. In your experience, what's the best way to advocate for the ACA replacement plans to have the same coverage as the state's Medicaid programs that they are supposed to replace.

>> I am going to take a -- to take a stab at this. We haven't addressed this specifically yet, but I think what I would recommend to somebody is that you should consider reaching out directly to the managers of those plans with various research in facts and ideas about how this has hindered people and how the state Medicaid programs were superior, whether it's broken down into talking points or a much more formal paper, and I would start there because if you can make your case about how there is a superior option to it and how these are failing, that can go relatively far in helping to make those changes. And if you have specific cases where you can highlight the personal stories about the five-hour drive and what that means, that can help you all, too.

>> The other thing you might take a look at, depending upon the state that you live in, there are a number of states that cover children under Medicaid regardless of family income. And we have been encouraging clinicians and families to determine if, in fact, the Medicaid plan would cover in their state. Medicaid covers hearing aids as well as Cochlear Implants. Of course, for children in all 50 states. So that would be another

place to check and just to determine if your state happens to cover. And then I think, what Nichole said is absolutely appropriate. I think that the other -- what you could make is if the plan that's not an ACA plan, for example, the Blue Cross Blue Shield plan, often some of the Blues cover hearing aids for children.

If the ACA plan wasn't covering, call their attention to the fact that the Blue plan covers. >> Another question that came in was about any stats or collaborations that you could speak of with Canadian organizations and any information regarding Canadian coverage or first nation stats? >> My understanding is that Canadian coverage is very different from ours in the U.S. From what I understand, and I haven't worked in Canada in a while. I used to. It varies depending upon where you are in the country. And subsequently, people were faced with challenges, and usually, it was wait times, depending upon where they lived. And adults were treated very differently from children. I think if I were you, and I were trying to get comparable coverage to what we have in the U.S., I would just call attention to what is done in the U.S. and make comparisons to whatever you are seeing going on in Canada. >> Yeah, I guess the other thing that I am thinking of is what's your best advice for the -- you know, we learned earlier that a lot of the folks on the live course today are audiologists. What do you want them to do? What is the movement that you want them to get behind, and what can they do kind of today to help push forward advocacy for their patients, you know, besides support ACI Alliance, what are the other kind of boots on the ground steps they can take today to push action? >> I would start with, you know, obviously we love it when people work with our organization on this issue, but, you know, since there are other organizations out there, is to also follow their advocacy efforts, as well, to get an understanding of kind of the broad overview that is happening.

And to kind of let them know that if they are interested, subscribe to advocacy alerts, follow various websites and newsletters. This is the start of a brand new legislative session as we all know with the wrap-up of elections. The calendars are just starting to get loaded with potential bills, so technically, there is nothing out there right now.

There is just a lot of potential bills that are out there, but -- so I would say to keep an eye out, especially when it comes to the advocacy side. But I would also encourage people to really think about areas where there are gaps, whether it's the fact that your state doesn't cover adults for Medicaid in your state, whether you have continually run into issues with unilateral hearing loss and coverage for CIs there.

And to kind of think about where you all would like to be involved and to let people know that you want to be involved in that. That's really kind of the first step forward. >> Do you have anything to add? >> I wanted to pick up on what Nichole said about Medicaid because it is an area where you can get change. We probably have seen our greatest number of successes in terms of Medicaid coverage for children and adults. And we can certainly help you in terms of knowing what to do on the process and suggesting resources that have been used. But, I have just been always impressed with how the state officials are responsive to hearing health care professionals as well as individuals in making changes to Medicaid coverage and regulations.

The one exception being how much the reimbursement is, and that one can be really difficult to get changes and increase the reimbursement. But I have actually been involved in efforts that have been able to increase reimbursement to the point where it was no longer an impediment and a barrier as it can be if the reimbursement is 10% of actual cost to the hospital. We have seen that in some places. >> I think one of the things I found in advocacy work within hearing care and other thing, my mom is a teacher, so I've been around this a lot with the teachers' union. Making yourself a resource to the elected official, as well. They don't know what the difference between severe and mild to moderate hearing loss is.

And so I have had success just reaching out to my elected officials and said, raise my hand and say, I am here when you need help interpreting a bill, when you need, you know, boots on the ground experience with what does this mean and how does this impact your constituency, I am here to be a sounding board to ask questions. Some

may ignore you. But others may take you up on that offer and include you in the pool of people to -- that they will reach out to you when they need help interpreting things, as well. Another question that came in, I would encourage audiologists to use your expert and be a voice of support for your patients.

All three of our kids are off label CI recipients, and their combined effort of our advocacy and insurance along with the efforts and submissions of our audiology SOP and MV team members open the door to our successes they enjoy today. So I love that. From a parent's perspective, reaching out and saying, you know, everybody on the team contributes to that. Maybe Nichole or Donna, if you want to speak more about how you can help as a provider, encourage those parents. >> Sure, absolutely. I have talked to various parents, especially the last year when it comes to single sided deafness, especially where there are denials after denials after denials even though a medical professional and a surgeon and everybody else is saying that the child would greatly benefit from this.

You were talking to a parent who is overwhelmed and distraught and trying to provide the best life for their child, and so they are feeling a little overwhelmed, feeling a little down, and they always, absolutely 100% tell me some of the biggest help that they get is from -- when the medical team provides the letter, provides the research, helps with the contacting of the insurance companies, and because, you know, most people don't interact with their insurance company much more beyond getting the explanation of benefiting and throwing it into a pile and paying the bill. So they don't know. They don't know how to work the system. Medical offices do. So that hand in hand partnership is something that I know parents greatly appreciate and benefit from.

So if you have a parent who is facing the denials, you know, helping them, craft a letter, reaching out to your colleagues who might know a bit more about this or who have already accomplished receiving approval for surgery for their own patients to figure out what they did, I mean, there is simple little things but the impact is huge. So

that partnership is, you know, part of the reason that we launched the CI this last year is the partnership between consumers and families as well as the medical community can do so much more than individuals on their own. >> Guys, this is incredible, and thank you very much for your advocacy and for your work. We so much appreciate both of you being here today to guide folks on how they can help impact positive change for the folks in their community that seek Cochlear Implant services.

Thanks so much, everybody. Thanks for all the great questions that came through. Any closing words, Donna and Nichole before I close it out? >> I think just -- this is Donna, and please do be in touch with us if we can help you, and we would love to have you be part of our advocacy network. So let us know if you would like to participate in any way. Nichole will do whatever she can to support you on that, and we would love to have you. The parent comment that we got just now is from a parent that is involved as a state champion from Alabama, and she really is great. And our state champs help one another, so join us and be part of our efforts.

>> I just have to echo what Donna said, so thank you, everybody. >> Awesome, thanks so much, everybody, have a wonderful day, and we will see you on the next audiology on-line course. Bye-bye. >> Bye.