Barriers to Enrolling Children with Hearing Loss in Early Intervention, in partnership with American Cochlear Implant Alliance

Presenter: Donna L. Sorkin, MA

Donna it's my pleasure to welcome back Donna Sorkin. She's the executive director at the American Cochlear Implant Alliance. If you'd like to learn more about Donna and her background, you can read her bio on the course registration page. But at this time, I'll hand the mic over to you. Donna thank you so much, Christy, for having us back.

And we're delighted to share information about negotiating the early intervention system and what healthcare providers need to know to support families and their children. This is a two part series and the first part was on the EHDI system. And in this part we're going to talk about barriers. So you may wonder why there's another organization in hearing health. And we were started about 12 years ago to focus on cochlear implants and particularly access to care.

And this series, of course, supports that aspect of our mission. And our members are audiologists as well as others across the continuum of cochlear implant care, as well as consumers and parents and advocates and hearing aid specialists. We have a website that we hope you will take a look at and we're highly collaborative with other organizations. And we also, of course, welcome your involvement. And we've given you a way to contact us and access our information from our website and Facebook and LinkedIn.

So this is our mission, to advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness. And we look at all of those factors that affect the ability of children and their parents and adults to access cochlear implants and of course, to increase awareness about candidacy and outcomes. So today we're going to talk specifically about early intervention. And what's really important about early intervention is that we're now screening 98% of babies. Huge change from where we were when I first got into this field 30 years ago.

And now we have that opportunity to work with children at the earliest possible time and eliminate some of those missed opportunities that were very characteristic years ago. And we know that some children

still are falling out. And we really are hopeful to improve awareness about how you can change that paradigm so that we have the opportunity to reach children early and so we can do better. And that's what we're looking at here, as well as what those barriers are. These are my disclosures, the limitations and risks associated with hearing care, the learning outcomes which are listed in the CEUs.

And let's start in with what is early intervention? And it was established actually in 2000 with the aim of identifying hearing loss in infants and Children. And this began a program to provide incentives to states to begin universal screening, which means that we screen every baby that's born in the United States. And prior to that legislation, children born with hearing loss were typically identified after two years of of age. And at that point, of course, it was very difficult to get them on track with language.

Interestingly, when we first started this program and I was in one of the organizations that was pushing for was opposed by a number of groups, including pediatricians, some of whom felt that if a parent thought their child has a disability, had a disability, it might interfere with their ability to bond with their. But we were able to convince people that maximizing language and literacy and enabling children to reach milestones. So typically hearing was so important that we really needed to move forward with this program. And it all begins with the hearing screen. And that little girl is obviously more than a newborn, but it's a nice picture of her getting a hearing screen.

So we included it. So here's a poll for you. How do you think hearing loss detection has changed over time? The first option is most babies born with hearing loss are identified within the first week of life. Secondly, it's improved, but about a quarter of children are still not identified until one year or later.

Or identification of newborns with hearing loss has changed little since federal hearing detection programs were initiated. Why don't you go ahead and promote vote on that now and we'll be able to see what your understanding of this issue is. It's really key to what I'm going to be talking about and of course to the advancement of children. So let's see what, what you all said. It's 13% thought it's within

the first week of life and 78% thought a quarter children are still not identified until they're one year age or older and the last one 9% is it's changed little.

Well, I'm happy to say that in fact we are identifying children within the first week of life. So that's the good news and the take home. But identification is just the first step of the process. And so let's explore that a little bit.

So the federal legislation that I mentioned was passed in 99, implemented in 2000 and at that time we were screening about 10% of newborns. So that was just some hospitals across the country and it has screened increased to the point that in a recent year, in fact we were screening 98% of children within the first week of life. So really good news on that score. And you can see a visual of this of how it's increased over time and really amazing opportunity and amazing change with initiation of that original legislation. Okay, so we screened the babies and then what happens?

And if the children don't then enter the system, that's what we call loss to follow up. And what you can see there is that there's three key milestones that we look at and there was issued goals from the Joint Committee on Infant Hearing some years ago, which is that we would screen by one month, we would confirm and diagnose hearing loss by three months, and that we would get the child into the early intervention system by six months of age. And what we have found is we are losing children after that initial screen. And the follow up is impacted by various factors that relate to the child. Whether they spent time in the intensive care unit of the hospital after their birth, the mother's education, poverty, what kind of insurance they have has a big effect.

The mother's race and ethnicity, where they live, if they're in a rural area, for example, or some areas of the country, the parents knowledge and whether the mom is part of some important networks. And we're going to talk about those networks. Those all have a really important impact on whether the child makes it quickly through the system. And this is a visual of what I'm talking about that was provided by

the center for Disease Control. The data was, and the slide was made by our friend Carl White at the national center for Hearing Assessment and Management.

And what you're looking at there as if the yellow is showing you the proportion of children who were screened within that one month period. And you can see it went down, it kept, continued to go up and then it went down in 2020, not unexpectedly because of COVID and I mentioned before, it's back up again now. It's actually at 98%. So that's yellow, that's the screening part of it. And then the orange line is the proportion of children who were not diagnosed by three months of age.

Remember I mentioned the 1, 3, 6. So in a recent year, 2020 again, things went south a little bit in 2020, but we're still around 28, 27% of children who are identified in the don't get diagnosed, don't get their hearing loss confirmed by a pediatric audiologist. And then that blue line at the bottom represents the proportion of children who then are diagnosed but don't enter the system, don't receive services, don't receive the follow up that's needed to ensure that that child's hearing loss is in fact Properly addressed. So that's what we're going to talk rest of the discussion today. So another poll for you.

What proportion of children who could benefit from hearing aids actually have them? Is it close to 90%, 50 to 60% or. We have no idea. So go ahead and vote for me. Put your vote in and that shouldn't take you very much time.

This is a simple question. Let's see what the answer is. Close to 90% is 19%. 50 to 60% of children get hearing aids who need them. That's 76% of you voted that way.

We have no idea. It's 5%. Guess what the answer is. We actually have no idea. There's no registry regarding children and their utilization of amplification.

And so we really have no concept at all of what proportion of children are getting hearing aids that need them. I actually posed that question to the three large hearing aid manufacturers and they had no clue. So that's just an interesting bit for you. So here's another poll for you on cochlear implants. So what proportion of U.S.

children who qualify for cochlear implant implantation have one or two cochlear implants? And so pick out one. Is it 90%? Is it 35% or is it 50%? And that percentage, you know, may be a little bit different than the hearing aid one, or maybe the same.

Let's see what you thought and I'll talk through what the results are. You said 90%. 11% of you said that, 35%, 46%, about half of you said that and 43% said 50%.

Good guess on that one. The answer actually is 50%. The reason we're there compared with 90% in many European countries, is that families are not getting information about follow up and the benefits of cochlear implants and if their child is a candidate. The reason we know that number and we don't have the hearing aid number is that as a Class 3 device, medical device, cochlear implants are registered and the manufacturers have information about everyone who has a cochlear implant in their country. And that's really important.

If something goes wrong or they want to notify the individual about aspects of their device, they know how to do that. So taking that information and knowing how many children are typically born with severe to profound hearing loss every year and how that changes over time, we have come up with that 50% number which has honestly not changed much much in the time that I have been working in this field and looking at that data so really important aspect of the whole barrier system that all of you can affect and have a role in because parents need information if they can take action for their child. And of course early intervention provides that opportunity for us. And it happens, if it happens the way it's supposed to and families do pursue appropriate services and technology for their children, whether

that's a hearing aid or a cochlear implant or a bone anchored device, it does lead to better auditory skills and language development. Broadly, it supports language, social interactions and cognitive benefits.

And the long term benefits of all of the above. And this is these benefits have been demonstrated by a number of studies over the years. And of course early sign language for those children whose families have selected that modality, also have the benefit of moving ahead with language at an early age. So regardless of the choices, if they happen early, they're going to contribute to better long term benefits for the children. This is an important study that I wanted to share with you that was published recently by Yvetzias and her colleagues.

It was published in JMA OTO and it's on cochlear implantation and educational quality of life outcomes in adolescents. It's data that was pulled from the long running cochlear Implant in children study that was led by John Diparco and his colleagues for over 10 years. What you're looking at there is the comparison of academic advancement in children that were in the study. And there were about 180 children that were in that cochlear implant study, all of whom were implanted relatively early. And comparing those children with children who had severe or profound hearing loss who did not receive cochlear implants.

That data set came from the US Department of Education's data on children who had an IEP in that same timeframe. What you're looking at is the vertical line in the middle of that graphic is 100%. It's what you would expect a typical child to be doing in terms of their language outcomes. The orange dots are those children who were implanted at or less than 18 months of age which at the time this study was begun was considered a very early cochlear implant. And of course now we're implanting many children at 9 months of age.

So the benefits are even greater because of the impact of neuroplasticity and the ability for children to start on their language learning journey. So those orange dots are kids that are at typical hearing or even better than typical hearing because they've had so much specialized therapy and focus with the family about really infusing language into the everyday life of that child. And that's not unusual. We find that to the extent that families are really motivated to help their children learn language and excel, they do more. I mean, and in describing the kind of therapy that we do with, with children who have received cochlear implants, I like to say it's good parenting times 10.

So it's all the things that you want to do with your children, but you do them more, and you do them more consciously. My son and his wife have heard me rant about this so much that I didn't think they were listening, but they were listening, and they're typically hearing. Child has amazing language, and it's because they talk to him all the time, and they talk to him with an advanced vocabulary, and he responds with an advanced vocabulary. What's also interesting about this chart is the blue dots are children who receive cochlear implants after 18 months of age. And they're close to typically hearing children that vertical line, but they are significantly less in their terms of their outcomes than the children that were before 18 months.

So that's why this whole business of getting kids into the system early is so important. And now look at those black dots. Those are the children who had the same level of hearing loss, severe to profound, but did not receive cochlear implants. And their language outcomes are significantly worse than that of the children who received cochlear implants. So this just demonstrates the whole opportunity that we see for early intervention.

Let's talk a little bit about children, hearing technology and Medicaid. And I'm going to spend a bit of time talking about Medicaid because it is so, so important as a potential barrier to the whole early intervention. So a bit of an overview to begin with. Medicaid is health care for persons of all ages whose

income and resources are insufficient to pay for health care. And there's a lot of discussion going on right now in national policy circles about what's going to happen with Medicaid in the future.

And honestly, our examination of Medicaid as a barrier began long before that national discussion began with the current administration, because we know how important it is to our population of kids. And you're going to see why in just a minute. Medicare and Medicaid were created in 1965 as part of the Great Society programs that were begun during Lyndon Johnson's time as president. They are separate programs, and they operate differently, but they were created at the same time in Our national history because of the recognition that people didn't have access to needed health care. Medicaid, unlike Medicare, is a joint program and it's funded primarily by the federal government, but it's carried out at the state level.

All of the 50 states have Medicaid programs for children and for adults. Adults. The coverage for children is much more comprehensive. And all states cover hearing care for eligible children, although those specifics are determined by each state. So depending upon where you live, the process may be different.

But your state does cover hearing care for children for sure.

So their role in serving deaf and hard of hearing children, again, this was established in 1967 by Congress and when Medicaid was actually begun as a program at the same time as Medicare, that was actually 1965. But then what happened was over time, Congress looked at what was happening in our country and they recognized that Medicaid was being rolled out differently in different states. And that wasn't their intent. And it was actually their intent to have more uniformity in the way children were served. They started a program called epsdt, Early Periodic Screening and Diagnosis Diagnostic Treatment.

And that was added to be very clear with states that this is something that Congress intended for them to work on. And interestingly, there has been an update to EPSDT recently. Very important to recognize that a lot of our kids in the United States are covered by Medicare decade. In 2023, that number was 37% of U.S. children.

And so this CMS guidance centers for Medicare and Medicaid Services issued guidance in September of 2024. And the intent of that guidance was to say that we want you to pay attention to the services provided to children. Because if we improve, if we address health care in children, we can ensure that children have better opportunities in life in general. And it specifically mentions hearing and it acknowledges the impact of poverty on health during childhood and beyond. So it is intended to guarantee services that are needed by children and it clarifies that those rules apply to every state.

So very important to know about the fact that EPSDT exists and that it covers children in your state. So these were part of this broad effort to comprehensively address children's health care. And again, it began with the War on Poverty, which was a bipartisan effort that was initiated in the mid-60s and EPSDT was added to that original Medicaid act in 1967 and really recognizes the special needs of low income children who are at risk for conditions that could then mean lifelong disabilities for those children. Interestingly, Medicaid hearing aid covers adults and children Differently, there's just very basic coverage for adults. Some states do cover hearing care for adults.

Hearing aids are covered in some states. Cochlear implants for adults are actually covered in about 2/3 of states. But the nature of the coverage is definitely not as extensive as it is for children. Because we know that addressing these impacts in a child will mean that they have greater opportunity for growth and development. And that's what the intent was.

So this was added later. The bottom line for you to know is that states can't decide that they won't provide specific services if those services are determined to be medically necessary. And hearing

assistance is one of those services. So if a clinician says a specific service is the best option for hearing restoration, Medicaid is supposed to provide it. And we sometimes have arguments and states about what that means.

I'm going to talk a little bit more about that later. But they're supposed to provide it. And you as a clinician can support a family that is having difficulty getting a needed service by saying that this is needed for that child's hearing access. So just posing a question to you. Will this enforcement change in the current environment where we're looking to cut Medicaid?

Will the provision of services change? Will the funding change? Because most of the funding for Medicaid at the present time does come from the federal government. There's some state contribution to it that's based on state specific factors. And so it varies by state.

But in all states, the bulk of it does come from the federal government. So children have to be covered for devices. All states cover children for hearing technology and for therapies. But the issues remain related to how the services are provided. So for hearing aids and cochlear implants and bone anchor devices, the things that can vary are, are replacement parts.

You know, sometimes children are rough on their technology and they need replacement parts. And some states can say, okay, we've replaced this twice, that's it. Different states have different rules about upgrades. How often you can replace a hearing aid or a cochlear implant. We've sometimes seen difficulties with provision of batteries.

Different devices have different battery needs. And so sometimes states have base the number of batteries that they'll provide on some arbitrary number that may not be enough for every child. And then, then you see families that have to ensure that their kids have enough batteries for when they're at school and maybe cutting them off for when, when they're at home. And then the other time we've

sometimes seen these rules vary is for A cochlear implant for a child. The FDA guideline now is nine months.

And if there's a medical reason, sometimes we're providing cochlear implants at an even younger age. But for example, in Florida they use a 12 month rule. So that's no longer the standard of care. If the child's identified and is healthy because of neuroplasticity issues and just getting the child going early, we want to do that as soon as possible. So that's a problem in some states.

I'm familiar with Florida because the advocates there are really trying to get medicine Medicaid to change that arbitrary timeline. And in some states a second device has been an issue. You know, one is enough kind of thinking. But clinicians should be able to argue that if a child has bilateral severe to profound hearing loss and can benefit from a second device, then you should be able to argue for that based on EPSDT rules.

So those services again have to be provided. But we really need to be aware of the impact of those rules and how they can affect access. And caregivers are supposed to be made aware and have access to the full range of services to meet a child's individual needs. And I think that's where you as clinicians can be really important in emphasizing that. We look at an assessment of the individual child and what that child needs to be successful.

And what's supposed to be happening with epsdt, which of course affects all children. Again, I'm talking about Medicaid because it has such a big impact. We know that 50% or more of children with hearing loss are covered by Medicaid because in many states the eligibility for Medicaid is based on not just on family income, it's also based on whether the child has a significant disability or health issue. So the majority of states now have opened up Medicaid to children who have significant health issues, including hearing loss. And so for example, MassHealth.

MassHealth, which is one I'm very familiar with in Massachusetts. Massachusetts, many families, regardless of income, have the ability to access mass health for their child in addition to their private health insurance program. So Medicaid is important because it has such a big effect on so many kids. And in talking about eligibility and services is states are supposed to use a range of written and oral methods, including social media platforms and electronic communications, along with handbooks and text messaging for reminders. And some of them are really great at this.

Some of them need to do better. And it turns out a lot of families actually use use the World Wide Web to access health information for their children related to hearing loss and other topics as well. So we feel at ACI alliance that those electronic means are hugely important. And we actually did a study recently that looked at the website for the early intervention agencies across the 50 states and we found that only about a third of them were doing what they were supposed to be doing in terms of providing complete information on options, on technology, on resources, on parent connections. So this is a really important element as well and something that, that we all need to try to remind early intervention that they need to be doing.

So another aspect that's really important for children that are covered by Medicaid is one of the reasons that we see for families not accessing services for not getting the diagnostic aspects, taking care of for their child is that transportation can be a problem and families are supposed to be informed that transportation assistance is available. But honestly, these systems are very complex and children and families need help in negotiating the system. And care coordination is an aspect of Medicaid that many people don't know about, but it can be covered under Medicaid under rehabilitation services benefit in section 1905. And interestingly, recently one of my colleagues and I were interviewing clinicians in California who were doing care coordination for children at night after hours, hours, because it was so complex for the families to make it through the system. They did not know that there was a code for care coordination that they could be charging to.

So really important, those children were covered by Medi cal, the Medicaid system in California. But people don't necessarily know that they can receive that kind of support, support that they need for this element. So how does Medicaid impact early intervention access? And kind of a summary of what I've been talking about, an important take home for all of you. So the first part of that graphic on the left side is about 50, 50%, maybe even a little more, of children with hearing loss, regardless of level of loss, are covered by Medicaid for hearing related care.

So that's a big proportion of our population of children. And across the states we see low and variable payment rates. I'm going to show show you some of those payment rates so you can see how low they are. But that impacts on access for everyone, whether the child's in Medicaid or not. And that low reimbursement plus high rate of no shows leads some providers to say, I don't accept Medicaid.

And we see that particularly in rural areas. But it's true regardless in many areas of the country. So this is a problem indeed that affects children generally. And here are some illustrative reimbursement rates for a few states that we looked at. And we just took some common codes that a child might, might, might need services related to.

Let's start at the bottom. The 92652 threshold ABR at diagnostic appointment. So remember, the child's screened and then the next step is we have to confirm and diagnose the hearing loss. And so they, that next appointment often utilizes an APR and the reimbursement. And we've done, we just took a couple of states, I guess there's six states there that we looked at and we compared reimbursement rates for these particular services to Medicare.

And of course Medicare doesn't cover children. So just in straight Medicare care. So we don't have those numbers for Medicare, but you can just see how much they're getting to perform that ABR test in six states. So it's variable. It's not super low.

It's low. And then the rescreening tests, the AAB test in those states does show you how low it can go and how variable it can be. So it ranges from $6 for that test in Nebraska up to $67 in South Carolina. South Carolina looks good because they spend a lot of time in that state meeting with Medicaid officials and trying to get those payment rates up so that children have more access to the providers, the pediatric audiologists that they need to see. And then that middle 1-92591 is a binaural hearing aid exam and selection and really like reimbursement for that, for that service.

And the next one up, we have a comparison with Medicare, but that's the, the CI device on how much Medicaid will reimburse for that. And it's, it's incredible how much of a differential there is depending upon on the state and versus Medicare, which reimburses 80% of the cost, which is around 40,000. So you can see how much less people are being paid under Medicaid. The California one is kind of misleading because in California, as I understand, the cochlear implant manufacturers contract directly with Medicaid, and so they're paid directly through the Medicaid office. So the hospital doesn't have to have a hit on that payment.

So zero is not really an accurate representation. It's probably the case that that's what's going on in Kentucky as well. And then at the top, what you see is the actual surgical procedure for a cochlear implant. And again, you can see how variable that depending upon the state and compared to Medicare. And South Carolina has great advocates and one of the clinics there really worked to get that number up so that they could perform that surgery for children without losing a boatload of money.

But this is just to show you how variable this is across the states and how low it is compared to Medicare. Medicare. So how does this impact on access? The reimbursement amount for specific services is determined by state Medicaid programs. It's all over the place.

I mentioned already that it's a good bit lower than Medicare or private insurance. Private insurance reimbursements are much harder to come by, but they're typically at or above Medicare. And in some

cases the reimbursement is so low that it's really negligible. 15% of cost is really becomes a problem for the provider. And when that happens, hospitals may terminate pediatric programs or put pressures on those programs.

And we know that that's happened. I've been involved in some advocacy efforts in some states where hospitals were threatening to stop providing hearing care because of the low reimbursement. So just to sum up, about 50% of children are covered by Medicaid. Variable payment rules across states can be different. Low payment delays and pre authorization managed care plans may not track straight Medicaid guidelines.

And sometimes there's so many of them that providers don't even know what they are. And it can be a very difficult and complex enrollment process and that can delay the care. So this is a summary of barriers in general, not limited to Medicaid, but including Medicaid. And we came up with this graphic based on a review of a lot of different studies that had been done on early intervention. And I took those and divided them into three categories, provider, patient and family.

And I'm going to walk you through those individually. But this is really a summary of what this talk is about. And you can download this and have it. It's one of the resources that we provide it. But let's talk first about provider system related barriers.

And that's affected by the availability of qualified pediatric audiologists and early interventionists that are skilled in working with infants and children who are deaf and hard of hearing. Because the reality is a lot of early intervention personnel don't have specific hearing loss experience. It depends on the state. It varies even within the state. I live in Virginia.

In Northern Virginia, where I live, the early intervention providers do have hearing loss experience. But if you go in some areas of the state that's not the case. They cover a whole range of disabilities in

children. Then there's the issue of getting an appointment for a diagnostic ABR within three months, which can be challenging. There are relatively few pediatric otolaryngologists and so you may not be able to get a physician that's specialized.

And many, perhaps most pediatricians are unfamiliar with hearing loss. Not unusual for them to say let's wait and see. And I know I've heard that from so many families that they don't necessarily get it, that time is of the essence. And so that who, what and when element really comes into play with providers and the ability of families to negotiate the system. There are also child barriers.

So if the child has other issues going on in addition to the hearing loss, if they're life threatening issues, they may need to have those taken care of first. If they've spent time, for example, in the neonatal intensive care unit, you've got to deal with that first before you start thinking about hearing loss, unilateral mild hearing loss, mar otitis media. Sometimes, sometimes people think that's not a big deal. I don't have to do anything about a mild hearing loss. He seems to hear is something you'll sometimes learn that the family hasn't gone ahead with it.

And then the last one noted there, it's the birth state not being the same as the state of residence. Linda Hazard, who spoke on the related talk for this is from Vermont, a relatively small state and sometimes the children who are Vermont residents may be born in New York or New Hampshire or somewhere else and so their records reside in that state and so they don't. They may not easily pick up those children. And so they're starting to to have agreements with neighboring states so that they can but that can be a barrier. So let's talk about the big one family related factors lack of understanding of the follow up need.

I mentioned pediatricians because they can be not particularly helpful or supportive of the need to move this and a lot of the studies that I read indicated that fathers are often more likely to be in denial than mothers. And so that can be a factor of not moving forward. And there can be subjective observations

of a child's response to sound or non acceptance of hearing hearing loss. I mentioned earlier, if the child has a mild hearing loss, it may seem that he or she hears. But there's also been a lot of studies that have shown that even a mild unilateral hearing loss that's untreated can affect a child's academic Potential.

So it's important, important to address all of these types of hearing loss at the earliest possible time. The family's work schedule, particularly if you know they're in a line of work that doesn't easily allow them to take off, to take a child to an appointment can be a big problem. Their socioeconomic aspects, whether they're lower income, low, lower education, if they have a different language than English, those are factors that can truly play into the follow up. And then the need to get to appointments can be very, very difficult for families that fall in that category. The type of insurance I've spent a lot of time talking about, but that comes up in all of the studies that I looked at with Medicaid, of course, being the disease difficult one, and then one that has come up over time and even in the present day is the presentation of the fact that there are options and not just guiding a family into one option.

And we feel it's really important that a family have a full understanding of what all those options, what all the communication options are, what all the technology options are early on to help them move forward in a productive manner. So we did three case studies to help us understand what some of these barriers are in three states. And we started with Ted, Texas and talk to some clinicians that are involved in hearing health care there. And the language barrier for enrolling or re enrolling is a key issue, especially after an automatic renewal had ended. And that was mentioned, there were concerns about physicians and others not providing full information or early urgency for follow up.

I mentioned that earlier, but it was mentioned as an issue in Texas. And in their case, when we talked about Medicaid and fees, et cetera, they said, well, it's not an issue in the larger hospitals, but it can be in individual providers or in smaller hospitals. So that made sense. And they mentioned that missed

appointments due to a lack of transportation slowed things down and made it difficult for them as providers. Sometimes the distances from where the family lived to where the appointments were created difficulty if they were relying on public transportation, if there was only one vehicle in the family.

So transportation was a big factor in Texas. And what was noted as a solution was utilizing Medicaid provided transportation. However, you have to ask for that three to five days in advance. The physician has to sometimes approve it, which can slow things down. And they're not always able to find a provider, especially in rural settings.

So let's move to California as another example. It was mentioned that the reimbursement was low. It didn't cover most costs hospitals run the programs at a loss and there may be limited number of providers that accept Medicaid. And then we saw that there were complications for enrollment in California's Children's services, which is Medicaid. And that can be complicated and cause delays for enrollees because of language barriers.

It's complicated for providers to get themselves approved because of the this system. And interestingly in LA county, which is where we talk to some clinicians, 80% of children have CCS but only a few centers except it. And for example there was only one center that that had an MRI that would take children enrolled in Medicaid. So there could be a backlog there if the child needed an mri. So location matters.

There can be a short term turnaround in an urban versus three to four months in rural areas and the service cover coverage and it follow from county to county. So a child receives services in one county, they may not necessarily be able to take that to another county. Our third case study was in Florida and what we found was that procedures and appointments were not always reimbursed. I mentioned earlier the problem with coverage for CI starting at 12 months. Months.

But if a child had meningitis they clearly would need it right away. And the FDA guideline is nine months. And the sheer numbers of Medicaid HMO plans with large coverage differences. There's no straight Medicaid in Florida so it's very difficult for the providers to track this. And the lack of knowledge on importance importance to a follow up from key providers and the plan of care must be signed off by a pediatrician in Florida.

And they also had a recent challenging element in which there was bias from early intervention about choice of modality and the provider. The early intervention provider said ASL is the language language of choice based on interpretation by some EI professionals. So obviously that's not the way this is supposed to be going. And even in this state they've had process or upgrades declined if the child uses asl. So very bizarre interpretations of things.

So case study summary Issues with reimbursement across the states Complications with the RE enrollment with Medicaid language, not English is a problem. Multiple steps and the impact of early intervention personnel and pediatricians not understanding the goals and urgency for follow up. So possible solutions Strengthen relationships with Medicaid staff staff work to increase reimbursement. Implement approaches that have helped in other states utilize the transportation that's available and the Medicare provider coordinators and also look for opportunities for mentoring and peer to peer. And then a really important one that was mentioned in a number of places.

Is is parent support and facilitating those connections to others. It in fact is noted in the EHDI legislation, but unfortunately it's often interpreted to mean capital D deaf mentors. But parents have repeatedly noted they want to have access to a range of perspectives and they especially want to talk to parents, parents of children who are deaf and hard of hearing and parents who have chosen different communication options. I really like the ability for parents to connect via organizations through clinics. Sometimes clinics have wonderful ways of connecting families and the online communities is a new

important way.

And of course, Hands and Voices, which is a national organization that has state chapters in most states. And one final note on the parent support aspect is fostering parent sensitivity. There actually are programs that help with that. It is undervalued as a way to improve language outcomes in children. So here's just a bit on the online communities.

Parents of children with Cochlear Implants is fantastic. It's a Facebook group with 20,000 members moderated by parent volunteers who are excellent. There's discussion and opportunity for posing questions to the group. It's a very supportive environment with all modalities represented. It's mostly us, but also from other countries.

I personally love the fact that sometimes parents have met each other on this Facebook page and then met up in person. It's a really great opportunity. Then a newer one is Parents of Children with Hearing Loss. It's a family Facebook group that's offered through hearing first. It has about 2,000 members and it is staffed and it provides materials.

And the members are by design listening and spoken language focused and positive about that particular communication option. So we've also given you some resources that you can follow up with after afterwards on Medicaid barriers. Graphic There's a study I did some years ago on Medicaid and cochlear implant access. And then we've given you a link to that recent federal guidance on EPSDT so that you can actually see what came out from that. And then I'm trying to see.

I don't see any questions. So please go ahead and ask any questions that you. That you may have at this time and I'll try to answer them. And I do want to thank you so much for attending and being part of this discussion. And I want to thank our wonderful hosts from Audiology Online who make it so easy and wonderful to present and reach all of you in a in a positive manner.

So thank you, Kimberly and Christy for working with us and giving us this opportunity. Again, it's. It's it's wonderful for everybody. And I should see if you all have anything to say at the end. Kimberly and Christy hi, Donna.

Thank you so much for that presentation. It doesn't look like we have any questions in the queue. You so I'll go ahead and close the classroom. Thank you so much for joining us. This course is going to be put together as a modular course in addition to Dr.

Linder Hazard's presentation from the week previous. And if you'd like to take that as a modular two course, two hour course, feel free to register for that. We do have one comment from member Kathleen. She said thank you. It was very informative.

So thank you for your comment. Kath. Kathleen, we'll go ahead and close the presentation now. Reminder just to take that exam should you wish to earn PE credit. Thank you again, Donna.