Early Hearing Detection and Intervention 101, in partnership with American Cochlear Implant Alliance

Presenter: Linda Hazard, EdD, MS

It's my pleasure to welcome our guest moderator today, Donna Sorkin from the American Cochlear Implant Alliance. This presentation is in partnership with acia. If you'd like to learn more about ACIA or all of the previous presentations that have been in partnership with us in the past, you can learn about them in our library at this time. I'll hand the mic over to you, Donna. Thank you so much.

It's an honor to be back with Audiology online and to welcome all of you to our session today on early hearing detection and intervention. And thank you everyone for being with us for this two part series. And this is to look at negotiating the early hearing detection intervention system, what hearing healthcare providers need to know about families and their children who are deaf and hard of hearing. And this is a two part series. So thank you for joining us for this first part in the series with Linda Hazard.

Our you could go to the next slide. So you might wonder who ACI alliance is if you haven't heard of us before. We are a membership organization that's focused on cochlear implants and access to care. And because access to care often means getting into the system and getting children identified at an early age, we are very interested in the whole topic of early intervention. And our members are cardiologists, their physicians, speech language pathologists, educators and others on cochlear implant teams, as well as consumers and parents and advocates and hearing aid specialists.

So all of those groups are welcome in the organization. We have a website that's designed for people who are in and out of cochlear implants and as our name implies, we are highly collaborative with other organizations. So please get involved. We'd love to have you involved. And we've given you our our website there as well as our Facebook page and our LinkedIn page as well where we put out a lot of information on social so next please.

This is our mission to advance access to the gift of hearing provided by cochlear implantation through research, advocacy and aware. We do look at all of these factors that contribute to underutilization and

attempt to improve awareness regarding candidacy and outcomes of utilization of appropriate technology. And we do that with a lot of different groups. Linda mentioned pediatricians, she mentioned the infectious disease, she will mention the infectious disease specialists that she met with in Vermont. So all of those are part of our access and awareness look at hearing health care.

Next slide please.

And we think this topic is critical because although we now screen 98% of babies for hearing loss, within one month of age. We do fall short on getting children into the hearing care system and these are missed opportunities because if we don't reach children early, the opportunity for them to reach language milestones is much greater if they enter early. And hearing health professionals are often unaware of why children fall out of the system and your role in ensuring that that doesn't happen. This series will look at how we can do better and how the system operates as well as barriers to early intervention services for children. Next slide please.

And I'm honored to introduce Dr. Linda Hasard, who is the program director for the Vermont Early Hearing Detection and Intervention Program and she's also an audiologist. Linda has been recognized as a leader in this field nationally and internationally. She's a past president, co president of the directors of speech and hearing programs in state health and welfare agencies. That's a mouthful.

And she has also been recognized in her own state of Vermont where she serves as an appointee of the governor on the Vermont Deaf Hard of Hearing and deafblind Advisory Council and the Vermont Interagency Coordinating Council. And she has also been awarded the highest recognition in the field of early intervention by her peers, the prestigious and Antonio Braxton Maxon Award for Eddie Excellence. So I'm thrilled to be able to share Linda with you as a real leader in this field. So with that off to you Linda. Thank you so much everyone for joining us.

Good morning everyone. And I just want to add to Donna's comments that I am really pleased to be here and honored to be here as well. My background is in both audiology and also educational leadership and policy. And along with my Vermont EDDY role, I am also I also oversee our early intervention Part C services for deaf and hard of hearing children as well as our school based some of our school based services with direct service for students who are mainstreamed in our schools in Vermont. So I'm going to go ahead and just I have my disclosures that you can see here.

Limitations and risks are here. Please please do review.

And these are the learning outcomes which I'll just review quickly. Describe the complex EHDI system of care, describe emerging initiatives in EHDI programs and explain how to collaborate with your state or territor program. So I'm going to move right into Eddy State and territory programs. Who are we? One of the quotes that I love that has been mentioned by Carl White who leads the national center for Hearing Assessment and Management is that state EHDI programs are different in every state.

If you know one EHDI program, you know one EHDI program. Some of US have legislation, some of us do not have legislation that guides the EHDI programs. So for instance, in Vermont we have administrative rules because Vermont doesn't like to legislate anything. So we follow administrative rules that guide our hospitals for hearing screening, diagnosis and early intervention. Other states like North Carolina, Iowa have, they have EHDI legislation that guides all of the work of the, of the EHDI system.

And some states like North Dakota do not have any legislation at this point in time. So there are struggles in those, those instances. So there are 50 states and nine territories that receive funding. The EHDI legislation is from birth to three years of age. I have been in the, with the ehdi system for 16 years now, prior to 2003, and the joint Commission on Infant Hearing coming together as a committee to look at what needs there were for children who were deaf, hard of hearing or deafblind.

Children on average were diagnosed with hearing differences between ages 3 and 5. Today, because of the EHDI legislation and because of EHDI programs being in the states and territories, we now have a very different view. And babies are being identified by three months of age. So the current EHDI legislation is from 2020, is from 2022 to 2026. And then we will be looking at reauthorization again.

And currently, just with where we stand in the, with the federal situation, you know, current federal situation, there will be a lot of work that's going to need to be done to ensure that EHDI legislation passes to ensure that our babies do have access to screening, diagnosis, early intervention and other really important expectations that I'll be reviewing in a little bit. So the EHDI federal legislation allows for both some grant, federal grant funding that has been in place since around 2003. It includes the, includes HRSA, the Health Resources Services Administration, and those funds I always call the touchy feely funds. So those are the ones that support a lot of the initiatives around our partnerships, which I will be describing in a little bit, as well as new initiatives. The cdc, on the other hand, is our second funder.

And that funds. Let me back up for a minute. So the HRSA funding funds all 59 states and territories. The CDC funding, on the other hand, funds around 39 states or territories. And there are some caveats with that funding in that you have to have a minimum of 5,000 births.

So that does discount. Some of our territories were less than those 5,000 births. And I'll be honest, Vermont is right on the edge of that 5,000. So I'm always excited when I know that we're above that level. And the CDC funding is really about the data.

So you can go to the CDC website for EHDI and you can see all of the data from the states and the territories. Right now, what you see on their site is aggregate testing or aggregate data. And it does look at the 1, 3, 6, so screened by one month, diagnosed by three months and into early intervention by

six months of age. And the data that currently is up there is the data for 2022. EHDI programs just submitted their 2023 data.

So that will be probably released sometime in May or June. But it's a great way to go back and look at the history of where we stand today as far as screening infants. In addition to the what we call the aggregate data, the 39 states and one territory that were involved in this most recent CDC grant, which will end in June, have been trialing what we call DE identified patient level data. And that will allow us to really do more comparisons. As I often will say, instead of with the aggregate data, we're kind of looking at apples to oranges depending on how states interpret the aggregate data that they're submitting.

Where the de identified level data is actually 179 different categories that we use to look at every single baby who's in the EHDI system at this point in time. That data is not currently being shared. And the reason for that is it's still part of a cooperative agreement with the cdc and at some point they will be figuring out how to release that data. Each state involved in this has a data sharing agreement with the cdc. Vermont is one of the current programs involved in this did identified data in October.

We submitted the 2023 data and we will be submitting a second set of data again in May. What I will say is that sometimes it feels like we spend a great deal of time on our reports to both the CDC and hrsa. But we are gaining so much information from both the data and the projects that we have going with hrsa.

Oops, my apologies. Skipped back there.

Thank you for your patience. So one other point that I want to make before I move on is that most EHDI states and territories have depended on CDC and HRSA funding, which is a little bit under $500,000 a year and it has been going down over the years. So sustainability is going to be something that EHDI programs are going to need to look at closely as we move through the next few years. Some states

have other funding. For example, Title 5 funding some states have in Vermont is one of newborn screening Fees also contribute to helping a little bit with the EHDI program.

And I will tell you, we are very, very lean programs, and that's by necessity. And we also do an enormous amount of work with a small number of staff to achieve.

So let's talk about the expectations now of EHDI programs. So we really are talking about tracking and surveillance, which are the national benchmarks which I've mentioned, you know, screening, hearing by one month of age. And in that situation, we collaborate with hospitals. So hospital screeners may be, may be nurses, they may be technicians hired for screening, or they may be outside vendors. And it depends on the state and it depends on the hospital as to what they choose, who to provide those services.

We also work closely with home birth midwives. And in 2010, very few babies in the states and territories received screenings by home birth midwives, primarily because the families did not want to come into the doctor's office or their pediatrician office. They had had their babies at home and felt like they were keeping them away from illness and bacteria. They definitely didn't want to go into hospitals. So a number of the states began trying to figure out how we could work with midwives and make sure that those babies also received hearing screenings.

And we were successful in doing that because at the time, HRSA allowed some funding for equipment, so for otoacoustic emission screening equipment. And many states provided midwives with the equipment, just as they have done with congenital heart disorder screening equipment, as well as newborn screening, the blood spot testing. We also, many of the states and the EHDI programs also began to partner with primary care offices because there are some states who do a two stage screening and some states that do what we call a one stage screening. So I often talk about the one, two, you know, the one, two, three or two strikes or three strikes in the sense that a baby may be

screened in the hospital as an inpatient and then may have a second screening before they're released. For states who do only the inpatient screening or the one stage, they will refer on if a baby doesn't pass a hearing screening at the inpatient level and they'll refer on for diagnostic testing.

In the case of the states and territories that use two stage, we like to do a screening, a third rescreen or third screening after discharge, and that is typically referred to audiologists or some or some of the screeners may have a screening day at the hospital. The hospital will do the rescreening. It also puts a lot of pressure on our pediatric audiologists. So we, several states have used primary care providers and have done trainings with them so that when those babies come in for their well baby visit, they can have their rescreening done there. And then if they do not pass, they are then referred on for diagnostic testing at that point in time.

So our second area is diagnostic evaluation by three months of age. So we collaborate with audiologists and we have seen a decrease in pediatric audiologists over the last several years. Really encouraging new people to come into the field and go into pediatric audiology has been really important. Looking at ways that we can help support audiologists so that these babies are able to get in by three months of age. Then the other area of the 136 is entrance into early intervention by six months of age.

And that sometimes has been a challenge and continues to be a challenge pre Covid. I think many states and territories did really well with the early intervention services. Then with COVID and post Covid, we have noted some real challenges with being able to encourage families to enter into early intervention. And those early intervention services may be provided by part C or they may be provided by non part C providers. Families do have the ability to refuse early intervention services.

And what we have seen a bit post Covid is the challenge of families being a little bit more concerned about having people come into their homes. We have also seen a lot more families who have

experienced trauma through the last few years and just kind of figuring out how can we encourage families to receive these very important services. Because as you know, even though children have been identified, getting to that next step of ensuring that they receive early children receive early intervention services is really critical. And I do want to make one more comment about EHDI programs because I think this is an important distinction for all of you to be aware of. So state EHDI programs and territory.

EHDI programs are responsible for babies born in their state. So there can be some challenges because if you are a resident of one state and your baby is born in a different state, then that state is responsible for tracking and surveillance of the 1 of the 1, 3 and 6. So for instance, in Vermont, and I'll just give you a few statistics, There are approximately 500 babies that are Vermont residents that are, I'm sorry, New York residents that are born in Vermont. So that means I am responsible for tracking those babies to ensure that they get diagnostic evaluations. And I'm also responsible for ensuring that they get into early intervention services.

On the flip side, There are about 900 babies that are born in New Hampshire or Massachusetts or New York. That is the responsibility of those states. So it gets a little complicated sometimes. But what's interesting is that the New England states, for example, we have data sharing agreements in place so that we can share our information with other states. Because once a baby, an infant is diagnosed, if they live in Vermont, for example, we want to ensure that they are getting the inter early intervention services.

Of interest is because of some state legislation, some states cannot share that information. And a good example is New York. So we are looking at ways to work around that with our key state partners because we want to ensure not only the babies that we identify are receiving the services, but we want to make sure that any resident of any state is aware of what those services are.

So some other challenges that we sometimes see in this 136 we call loss to documentation because we are not always able to. You know, sometimes a report doesn't get to the Vermont EHDI program or another state EHDI program. And so we are tracking down those reports. Some babies may be referred or sent to a NICU in another state because of significant medical challenges. So again, working to have those data sharing agreements is important.

In addition to that, with hipaa there is the exception which means that we can, if it is a continuum of care, we should be able to get that information fairly easily. One thing that I love in our health network system is that we have access to the electronic medical records. So our program doesn't necessarily need to wait to get a diagnostic report. We can go right into the EMR and look at that information and then ensure that those next steps are happening. For the referral to early intervention, we also just encourage meeting and talking about how to make sure those referrals go on for happen quickly for early intervention services.

So I will also mention that, you know, programs state EHDI programs as part of this 136 are offering hospital site visits. Those may be in person. They may also be virtually just to update especially when there are changes to the staff that are conducting the newborn hearing screening. Also primary care screeners in primary care, we want to make sure that everyone who is screening babies is following the same protocols or the same training. And the national center for Technical Assessment and Management is, is really wonderful and cham about having training videos for screeners and we use them all the time so that we have consistent across screeners throughout the US So some of the.

So the HRSA grant we currently have a five year. So we are, we have just, we will be just ending year one on March 31st. It will go until March 31st of 2029 and one of the initiatives in the new HRSA funding, besides the 136 tracking and surveillance, is expectations around language and developmental assessments. This is certainly we have certainly broadened EHDI programs over the

years. When we initially started in 2003, we were really birth to one year.

So we were really looking at that 1, 3, 6 only. And the latest legislation or the last couple that have been passed at the federal level are really about birth to three years of age. So the most recent HRSA award, which is a grant award, is asking EHDI programs to work on not just screening diagnosis, but also family support, early periodic screening, and also ensuring that there is baseline data by the end of year five. So by the end of March of 2029 that we have baseline data on three year olds enrolled in early intervention who are deaf or hard of hearing sharing. Although EHDI programs are being asked to do this part C and non Part C, so OSEP the same requirements are not on part C and non Part C programs, which is presenting a challenge for EHDI programs in a couple ways.

Number one, we are trying to figure out data sharing agreements with our early intervention providers, whether they're part C or their non part C. And we don't really have any authority. So trying to figure out those relationships can be a bit challenging. The other issue with the language assessments, how it is written in the HRSA grant, is that they want data, baseline data at 36 months of age. And in most states and territories, that child will have already moved from part C services to Part B services.

So for some states, language is the early intervention services are covered under the Agency of Human Services and not the Department of Education. In other states they fall under the same entity. But it does present challenges. So many of us, when we were writing the grant, went ahead and just stated that we do not have the ability because that child has now moved into Part B services to provide the language assessments at age 36 months. So we put in other proposals at that point in time that we would be able to provide when we would be able to potentially provide those language and developmental assessments.

So the CDC had given out a cooperative agreement a few years ago to the University of Colorado, and the program was called Odyssey, and they began studying language assessments and developmental

assessments for children enrolled in early intervention. Vermont was one of those 17 states that was invited to participate in that program and we started in 2021. And I'm going to share quite a bit of the data that was just recently presented at the EHDI national meeting because I Think it is important to see what is happening in these areas with at least a small number of states, since this is one of the EHDI expectations. One of the other challenges about the language assessments and developmental assessments is that we don't have a standard for what assessments should be used with children in early intervention and state to state. There are going to be differences.

So as we begin to look at this process, we know that we're not going to be able to necessarily compare state to state. The Odyssey Project ended in August of 2024, but the university of Colorado has begun an early language outcome takeoff from the Odyssey Project. And of the 17 states, 12 have remained, including Vermont. And we are able to use some of our HRSA funding to support that continued work. So typically we are seeing the MacArthur Bates communicative development Inventories, the Developmental Assessment of young children, DAC2 being used.

And then as part of the Odyssey Project and kind of Vermont's philosophy towards language and literacy, we also added the sky High to the assessments.

So I'm going to go through just the Vermont ehdi. And our early intervention program is called the Parent Infant Program. So it is a part C program. All children who are deaf or hard of hearing or deafblind qualify for services. In addition to children who are diagnosed at birth, we also include children who have a conductive hearing loss for more than six months.

So if it's a fluctuating hearing loss and they have had six months of challenges, they are also included in our early intervention services. We have a data sharing agreement or a business associates agreement with the University of Colorado to share that data. And one really important, important piece that I want to share about some states and Vermont is included in this. We use qualified, specialized

and licensed providers in our early intervention program who are providing services to deaf, hard of hearing and deafblind children. So that includes teachers of the deaf and hard of hearing, it includes speech and language pathologists, and also includes educational audiologist.

And I did want to mention that when we are using our three tests, Sky High, MacArthur Bates and Dacy 2, because they are in part B at 36 months, we elected to do all three of those measures starting at 8 months, 14 months, 20 months, months, 26 months and 32 months. And we do give all three. There are some programs that Part C programs have found that providing or being able to do three assessments at different age, you know, at different age groups is really challenging. But we felt that it was, it was really important to collect that data as part of both the Odyssey Project and now The Early Language Outcome Project or elo.

So I'm going to give you a little bit of demographics. So as I mentioned earlier, these what I love about this project right now is that the Vermont data is compared to all 17 states that are enrolled. Starting next year we will have 12 states that we will have additional data on. And we do look at the demographics, demographic data, and you can see that there's differences between UVM and ELO. Vermont continues to be 96% white.

And we do, although we do have a lot of who we call new Americans who have come into the state in the last few years. But we continue to have a really low Hispanic ethnicity and very high white race in the state of Vermont.

So we do also collect information on sex, race and ethnicity. And you can see in comparison between us and the elo, we're very similar, similar as far as boy versus girl and then again the non Hispanic and the Hispanic. And as we mentioned that we are definitely a state that still is very, very white. I will say that we look also at the type of family support our families have as part of this project and we also look at family support. We infuse parent leadership into this and parent family to family support because we

feel like it's really important in all aspects of the system.

So this slide looks at disabilities and audiology variables. You can see 74% of the children in our program have no additional disabilities and 26% do. It's also very similar to the Elo statistics. And one of the reasons as we go forward with this HRSA funding and looking at language assessments, I do think it's really important to better understand understand the language and literacy of children who have additional disabilities and those who do not have additional disabilities. I wanted to provide this information so you could look at each of the variables that we do look at.

And I know these slides will be provided to you as part of the course that you're taking today. So we looked also look at hearing levels, bilateral and unilateral hearing differences. And again you can see some similarities and some differences between Vermont and the elo. And one of the big differences is the number of profoundly deaf children that are identified in Vermont. And you could say, well, are you missing them as compared to some of the other states?

And I've been practicing for about 35 years in Vermont and this has been very typical. We see a bit one baby with profound hearing loss every two years.

So hearing technology, you can see the comparison of children who are using hearing aids, cochlear implants cochlear implant and hearing aid and bone conduction aids and those children who are not using any hearing technology. And I will clarify for you that Vermont does have a higher rate and that is primarily because of the fact that we also do service children who have long standing conductive hearing loss between birth and three years of age. And we feel that it's just an important aspect of ensuring that children's language and literacy in those early years are being addressed.

Next we'll talk a little bit about. I'll talk a little bit about the communication mode. You can see that we are very close with primarily spoken language between us and the other 17 states. Spoken language

we are a little bit lower but again higher with spoken language with occasional sign and then you can see sign in spoken language a little bit higher than the ELO and sign language in this group only. Currently we do not have any early intervention children just using sign only.

So this is just to give you some information on the scores of the Dacy 2. These are children with no additional disabilities and you can see that they're fairly similar. The one that really stands out and the one that we have seen where Vermont is much lower is with the gross motor skills, which has been an interesting finding that we're really looking into. And that's why I love the fact that we are looking more closely at these language and developmental assessments because I think that it will be helpful as we continue working with children in early intervention. The day C2 average range, again you can see some really fairly similar information on cognitive.

I will comment that we are a little bit lower in the cognitive area right now and we are looking into better understanding what and again this is with no additional disabilities. So we want to delve further into what may be going on and how we can provide improved services to help these children and the MacArthur Bates. What I find really interesting is that you know this, this information with expressive vocabulary, again very similar between the the groups the 17 states and and the University of Vermont Parent infant program and MacArthur words and sentences, again bilateral children a little bit lower than the comparison of the children enrolled a little bit higher for bilateral children with the three longest utterances. So also very interesting just to see these comparisons and the sky high you can see the differences here between those children enrolled. So again some similarities with Vermont children being a little bit higher in the area of the unilateral and I'm sorry the expressive language and the receptive language for our unilateral and of interest, I just do want to point out this one statistic which is that about 1/3 of children born in the US today have a unilateral hearing loss.

And I should also explain a little bit about the Sky High. It's a criterion referenced assessment and provides responsibility results in terms of age scores. Because it's not norm referenced, standard scores and percentile ranks are not available. So in order for us to compare the child's age scores to their chronological age, language quotients were calculated. They were derived by dividing the child's age score on the Sky High by their chronological age.

A language quotient of 100 indicates that a child's age score was equal to their chronological age. A quotient of age indicates that they are functioning in terms of language at 80% of their chronological age. And again, there were no additional disabilities here.

So why are language assessments important? Because they analyze the language acquisition and milestones. We are looking at them based on region, race, ethnicity, gender, gender, family structure, socioeconomic status, family structure and parent education. Our goal here is to identify services so that we can improve and enhance language acquisition. These results are shared with families and we do work closely with families to identify some ways that we may be able to modify those services and to improve those services.

The other area that all of us will be looking at, the new CDC grant starts July 1st. So the 39 states, there are two components in this Component A will continue to work on the DE identified data and Component B will really look at being able to add fields to our data systems to collect the language and developmental assessment data. So for Vermont we're hoping that we will be able to do a data exchange or extraction that will go directly into our data system once we are able to provide those to do the enhancements around collecting the data which will be really helpful or the other option for many states will be to work with their part C or non part C providers and have some type of data sharing agreement.

And I will say that one of the challenges for many states in collecting this information is that Vermont has one single point of entry and the majority of states do not have that. They have multiple part C and non part C program programs. So really trying to standardize this. In hindsight, I really wish that HRSA had worked with us to provide so that we could have done that first before delving into this. So I want to move away from the language piece, which is a high focus in this five year cycle, into family engagement and family based organizations.

Over the last many years these have become very important initiatives to ensure that families are our partners. And I absolutely love the fact that we have families at the table. So there are hands and voices, there's family voices in states and then there are other family to family support organizations. So be sure to look and know check out some of these resources. I'm happy to send links to some of the information we are finding that family to family support and parent leaders can make a big difference in families choosing to move from being diagnosed or their child being diagnosed into early intervention.

Many states we are providing a parent leave leader or parent leaders that will work with that family through from diagnosis into the early intervention services. So another area that we have always monitored which is those infants with high risk factors for developing changes in hearing so for developing acquired or progressive hearing loss. So so one to three babies at birth per thousand are diagnosed as deaf, hard of hearing or deafblind and between 6 months of age and kindergarten age that doubles. So there are a lot of children who will have will develop or develop acquired or progressive hearing loss. And so one of the areas right now that are one of the areas that we've worked on for years is, is making sure that we monitor those babies with high risk factories factors, not factories.

One risk factor that always stands out to me is that if a parent comes in and says my child doesn't seem to be hearing, that should be a huge red flag. And we know that for many years that sometimes that

isn't acknowledged, particularly in the pediatric offices. So educating the pediatrician is also a key initiative which I will chat about in a few moments as well. Some other programs that are part of our expectations are ensuring deaf and hard of hearing mentor programs so that families and their children have access to adults who are deaf or hard of hearing. And that is something that can be very, very important as children grow and develop to have those role models.

Further expectations include website development. Every year at the Edding conference, one of the states wins the website development, sorry, the website year award of the year. And that is because we're encouraged to keep updating and make sure there's resources for families. So I encourage you to check out your state EHDI website. There is a lot of information there.

I will say, however, some states really do not allow a lot of information. So it depends on the state and whether or not what information can be included in the website. So this year Michigan won the website of the year. Did some great things and it was really fun to, you know, to see them have that, you know, have that opportunity because it encourages us all to improve our websites Also I will say a couple years ago, Donna Sorkin from the acia they reviewed websites and really gave us some good information about how we can improve our websites to make them more interesting for families and for professionals. Some other expectations that we have include family retreats, parent professional trainings and this picture is from a retreat that Vermont held.

Actually we invited the New England area as well as Vermont and we had a wonderful parent and professional retreat weekend. Families came with their children and daycare was provided for all children. Families had time to process with other families. They were able to have some presentations that were really helpful. It was one of the best experiences I have ever had.

The CARE project is who provided that training. Other trainings that states will do and we have all done as well is trauma informed and holding space workshops with both parent professionals and what I love

about some of this work is that parents and professionals actually come together and talk and the bonds that we form going forward with our parent leaders is truly amazing and it really makes the work of Eddie just easier fun and there's lots to do. So EHDI Advisory Councils Every state and territory is required to have an advisory council that includes parents, professionals, deaf and hard of hearing adults. And it is truly a place where work can be done and we can look at the vision how we can improve EHDI programs, how we can improve school based services, services for children as well. Another initiative is the family committees.

It's really important to have families involved with reviewing resources, with reviewing websites and state EHDI programs have brought it, you know, have ensured that our family leaders and parents are involved in all of the work that EHDI is doing especially around resource sources or state and territory programs.

So what if, excuse me, what are some of the emerging issues that we're being asked or initiatives that we're being asked to help work on? One is congenital cytomegalovirus and the second one is early periodic screening for children birth to three years of age. The last one was involved in the newest legislation and it is because of the number of children that have acquired or progressive hearing loss cmv. One of the biggest challenges with congenital CMV is the lack of knowledge that women of childbearing age have. 91% of women have never heard of congenital CMV and they are also not There is no prenatal information around CMV in many states.

In most states. So one of the biggest challenges is the American is obstetrics and gynecology. So acog because they are really against informing families around cmv. So all EHDI programs are working on this initiative. Some states, such as the only state in the US currently that is doing universal screening of all babies for congenital CMV is Minnesota.

And they're doing the blood spot and then confirming with urine. There are a number of states, which I'll show you in just a minute, that have some sort of legislation involved with either education for families prenatally and also that may do more of a targeted screening where babies who do not pass a hearing screening receive. They would receive a CNVC screening. So there are some things around the education that I want to point out. First of all, somewhere between 50 and 80% of people in the US have CMV.

It remains in your body for your life. It comes across as a virus, a cold. It's nothing that is urgent. However, it is very difficult. Different if a mom is pregnant and has an active CMV infection.

So about one out of 200 babies are born with congenital CMV. Some of those babies will have active CMV and some will not. But in the cases of those children who do not, monitoring is a very important piece to the cmv, to CMV monitoring or monitoring of those children, especially with hearing loss. So what are some of the things you can do to protect yourself when kissing a young child? Try to avoid contact with saliva.

So don't kiss on the mouth, kiss on the cheek or the forehead. Don't share food, don't share pacifiers. Don't drink out of their cup. When changing diapers or wiping a child's nose, make sure you wash your hands. So I'll just give you a quick little story about the infectious disease doc in Vermont who I met with to talk a little bit about this and or our committee met with.

And he is adamantly against educating women about congenital CMV because he feels it will scare them and he doesn't want to do that and that we should not be informing women of this. And yet we know that it's really important for them to know about, especially given the numbers that are continuing to rise with cmb. And so it is somewhat frustrating. So we continue to try to work in our states with education for OBGYNs and for others. And you know, there are so many other aspects of CMV that in addition to hearing loss, so microcephaly, liver issues, heart issues, and so it is important to recognize.

I would encourage you to go to the CMV website, which is just nationalcmv.org where you can see some additional information around this very important initiative. And here you can see the states in blue that have some type of legislation in the United States. And yes, Vermont does not. We are waiting for it to be added to the rusp, which is what guides conditions that we can add to our administrative rules. Some states have to wait for that before they can pass legislation.

However, in saying that, I will say that Vermont we do do targeted screening. So any baby who does not pass a final screening and goes on for diagnostics does receive a saliva swab and we do the screening for them and then we will confirm with urine if there's any question. What's also interesting is I pulled the data before I came to this presentation because I just wanted to quickly know what our looked like. So for our hospital who does the majority of our pediatric diagnostic evaluations in 2024, 81 babies were screened. That does not include the numbers from our southern birth hospitals who also do screening on any baby who does not pass an inpatient hearing screening.

So I'm sure you'll be learning and hearing more. There is a CMV conference that comes up every other year. The next one will be, I think this fall in Minnesot Soda. And if you want to read a little bit more about cmv, there are some really good books by parents out there and I'd be happy to share that information with you. So another goal that we have is early periodic screening for children birth to three years of age.

And that gets a little bit challenging to implement because pediatricians just don't have the time to screen every child. They don't have the equipment to screen every child at once 2 and 3 years of age. But again, given the statistics of the number of children with acquired and progressive hearing loss doubling between six months in kindergarten is something that we're really trying to work on and trying to partner. But again, EHDI can't do it all. We need to partner with other agencies and other providers.

So one of the initiatives that started in 201010 was the Early Childhood Hearing Outreach. It's called the ECHO program under NCHAM and there was a national Early Head Start collaboration that supported programs to implement hearing screening using OAE screening. So an objective measure and doing that between birth and three and then continue to do that between ages three and five as well. The ECHO project covered equipment supplies and annual calibration and EHDI programs help support that by doing training of all staff. We continue to do that in our program.

Early Head Start programs felt it was so important that they have continued to buy equipment because much of what was provided in 202010 is now on its last legs. So looking for other ways to find funding through grants and other avenues to provide this really important screening to these littles I love this quote. The best teacher in the world is the one who loves what he or she does and just loves it in front of you. This is Fred Rogers. This was presented at the EDDY National Meeting last week by one of our plenary speakers and I just want to comment on on EDDIE programs.

We love what we do. We are dedicated. We are in this together. We work really really hard to try to address the initiatives we're being asked to address. And I really invite you into our space to come and get to know us.

And I also would say there is so much learning at this EDDY National Meeting for for EHDI programs, parents and providers of early intervention services and yes even some school based services. So it's so I just wanted to include this as part of the presentation.

Current State continued so supporting EHDI programs the directors of speech and hearing programs and state health and welfare agencies which Donna mentioned earlier earlier. We are really what I would say the voice of Eddy. I served in a co presidency for 10 years because of some challenges that we were having at the federal level and then Covid and we also have representatives who serve on the national committees including jcih. The national center for Hearing Assessment and Measurement.

NJAM has been a valuable national technical resource center for us for 255 years.

This past year they did not receive the funding through the grant, but they continue to partner with us and work on important initiatives. If you go to their website there is an amazing amount of information including the Journal of Early Hearing Detection and Intervention, a roadmap of the 136. Additionally, our federal partners who received funding through HRSA this past year year include the Implementation and Change center which is the Beacon center out of Gallaudet University, the Family Leadership and Language and Learning and the Provider Education center which is the American Academy of Pediatrics. All of these sites have great resources. We are looking forward to the AAP working more closely with pediatricians because we feel that's an area of partnership and of training about the EHDI programs.

That is is really an important aspect. Current State of EHDI we know that future funding of EHDI with the legislation coming up is obviously of concern. Expansion of requirements is always concerned. We seem to receive less money with more initiatives to work on. And again the authorization right now that we have is through 2020 26.

So how can you partner with your state and EHDI program? I encourage you to reach out to your state EHDI coordinator. You can Find all their names and all of our contact information is on the NCHAM website. We have state stakeholder meetings annually after the EHDI conference. And so that's a great opportunity to find more information about EHDI programs.

You know, understand the issues for your state. Every state's different. The issues may be very dis different. Participate in state level advisory councils, participating in learning communities and be vocal, share your opinions and think about, you know, attending some of the conferences that are out there like the Hands and Voices Leadership or the EDDY conference. There are the aci.

You know, there are so many opportunities, opportunities to learn more about EHDI and learn more about the initiatives for early intervention services. And I will just end with saying I always put this picture up because maple sugaring season in Vermont and these are the maple sugar twins.

And Donna, I'm turning it back over to you, I think. Sure. Linda, thanks so much for an amazing presentation on the program and sharing some data that I personally have no seen before. So it was really very informative and I like the fact that you were across Vermont and the, the national scene as well. I don't see any questions if, if any of you have those.

We can, we can take them now and you can just type them into the Q and A box which you can see at the bottom of your screen. I have one question that I'd like to ask you, Linda, and hopefully people will join in and put their questions in as well. You talked a bit about the language acquisition data that you had in Vermont and some comparative to other states. Do you feel like most states have the ability to assess children with this? Along these lines?

I think it's going to be challenging, Donna, because there's no standard approach to what assessments should be used with children. And there are so many differing opinions and I, I do think that it's going to be very challenging to get some of those data sharing agreements in place to come to agreement on what assessments should be used, how many should be used. So I think there's a lot of challenges. What I will say is that HRSA has shared with us that even if a state only works with 1 part C or non part C program, that's fine. It's really to push at least getting some data by the end of year five.

But there are many, many, many challenges in front of us. And I think that Congress has supplied money federally, we've received money for a long time. And one of the questions that comes up is, well, we are screening, diagnosing into early intervention, not overall by six months but you know, children are getting in, so how are they doing? Is this making a difference? And I think that's one of the reasons why the language and developmental assessments are important.

I just sort of wish we had a structure in place prior to these requirements. I think it would have. Would have been helpful. And it's going to take a village to do this. Yes.

Thank you, Linda. I agree with you. I think Vermont being a small state and with having the leadership that is it does yourself and others on your staff really puts you in a very special position. So we thank you very much for sharing that and also for your honesty in talking about any programs nationally in a, in a positive but honest way. Thank you for joining us.

And Linda, thank you for a presentation on a topic that I learned so much, much on from you. I always learn a lot from you. So thank you. And thank you also to our partner, Audiology Online, for having us back again and for always hosting in such a tech savvy manner. Makes it easy to present.

So thank you very much, everyone. See you next. Thank you, everyone. Thank you, Donna. Thank you, Dr.

Hazard. And. And Linda, if you can just advance to the very last slide. Just to remind our participants that there is an exam should they wish to earn CE credit. This concludes the content portion of the presentation.