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EHDI Annual Conference 2024 - Topical Session 5 & 6

3/19/24

9:10 AM - 11:55 AM (MT)

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START TIME: 9:10 AM

(Captioner Standing By).

>>STEPHANIE BROWNING MCVICAR: Welcome, everyone. Every two jobs, one to keep the time for our presenter and the other is to remind you to go to the app or conference agenda to fill out evaluation after the session.

>> Okay everybody. Feel free to move up closer to see the slides if you want. The slides will be posted online, the conference app. If you need anything else, e-mail me as well. So, good morning, I'm Stephanie Browning McVicar.

Can you hear me in the back? Some great things happened in the congenital cytomegalovirus world in the past 8, 9 months and we had a national position statement that was passed last June that has taken effect January of this year.

So I'm going to share some tips and tricks with you on how you can interpret the new

position statement and how you can use it to guide your congenital cytomegalovirus surveillance and I'm going to help you learn how to identify the classifications in the position statement for congenital cytomegalovirus infection versus congenital cytomegalovirus disease and focus on the timelines that help us determine and classify laboratory evidence.

Can I see a show of happens if your jurisdiction is completing surveillance of congenital cytomegalovirus cases? Just shout out your states or jurisdictions? Okay. The usual suspects. Excellent. So in Utah we have three EHDI programings our main hallmark program, I'm not going to explain the acronym. Never mind, our congenital cytomegalovirus public health initiative known as public education and testing program and then our children's hearing aid program, so three state programs are involved infant and childhood hearing. We have two types of screening, hearing targeted screening and high risk targeted screening.

Hearing targeted screening is a direct result of our legislation. I can't believe it will be 11 years already. Time flies when you're having fun. So in 2013 our law stated if an infant a newborn hearing screening we need to test for congenital cytomegalovirus before 21 days of age. Critical window.

We further defined our law in rule by stating that if infant fails initial or inpatient hearing screening and their outpatient, second hearing screening, they need to be tested for congenital cytomegalovirus. We are one of the states that have the two stages. If a baby fails their first screening if already 14 days oils they had need to be tested. Medical practitioners when get the lab results send to us. We made an a lot more robust when we added congenital cytomegalovirus testing reporting to us through communicable disease and reporting rule in 2015, so since that time, any infant under 12 months of age who undergoing a congenital cytomegalovirus test, no matter the results, they're sent to the department.

Now, fast forward from 2013 to 2019 and we have a CMV working group and it's

researchers, public health specialists providers for CMV clinic we have, we call primary children's chapter, that's a children's hospital in Utah. We put together a high risk testing protocol. It's hard to see. If you want it e-mail me and I'll send you the full protocol. I highlighted 11 risk factors and if they are present -- not much sleep -- so if any are present a CMV test should be done before 21 days of age. This took effect in late 2019 and I forgot I had my daisy in my hair, late 2019 in the fall, all healthcare birthing hospitals, the largest healthcare hospital in Utah and a couple other hospitals practice this high risk testing, that represents a little over half of all birthing hospitals in Utah are following high risk testing protocol.

So a huge increase in number of tests conducted because of high risk testing protocol. The number of cases are the blue columns and you can see there's a huge spike during COVID. Doesn't make sense. Well it was because at the very end of 2019, that protocol was starting to be instituted and fully instituted in 2021, so there was a lot of them. The biggest risk is the numbers even though the tests in the thousands were lower in 2021. That's the impact of the pandemic.

So let's go back in time, the beginning of January to June of 2022 our experts and friends at CDC decided to do a survey to see echos conducting congenital cytomegalovirus across the US. They surveyed all 50 state health departments, they found they were different ascertainment methods being used, so there was no continuity, it was very heterogeneous, so it's difficult to compare incidence and prevalence across the US when looking at case counts differently. So we were one of the states they did an interview with and they said we're thinking on working on a position statement, do you want to help us? We said sure.

What is a position statement, for those of you who haven't heard this in the public health arena, the Council of State and Territorial Epidemiologists or CSTE attraction were the ones

that instituted national position statements. So in the '80s they started having position statements and now over 7 hundred in their library.

We pursued one for standardized surveillance. Some conditions when he try to write a position statement will pursue standardized surveillance but also try to make it a nationally notifiable condition and we chose not to go that route at this time because it's difficult to get to pass, a regular surveillance position statement. It felt like 8 thousand steps to get us to our position statement.

So we didn't go for the NNC and we went for the standardized surveillance to start. Doesn't mean in the future we can't pursue that option. There are many contributors to the position statement. We had coauthors and authors and many subject matter experts for our specific team we had the Utah team, CCT team, two-dozen subject matter experts across the US and in core working group 13 public health officials and in our large working group we had 65 individuals that provided us input in the writing and, in addition, to this, as we go throughout the process we continue to present to CSTE to the member, and then also to all this state epidemiologists as well and they provide, comment and suggest edits.

It's a comprehensive process. So every position statement follows the same, not agenda, the protocol process. Not the word but you know what I'm taking about. The outline is all the same. I'm going to highlight three tables that are super important to get the gist of it, so you can start using the position statement for your surveillance. So we're going to start with table five, the recommended sources of data. Where can a case report come from? So they can come from clinics and labs and hospitals. They can come from early intervention agencies and come from EHDI.

They can come from death certificates, vital records, autopsy reports, birth defects, registries, so many places where CMV can be reported from including strong medical records.

So how can these determine whether a case should be reported to public health? So in all the states doing the surveillance coming to department of Health and Human Services. I know LA County -- anyone from Los Angeles? We've worked with them because LA County is trying to collect case data, so the laboratory criteria for reporting is as follows, the Ss stand for sufficient, so if one of those line items present it's sufficient to report a case.

So detection of CMV DNA by NNAT. It's nucleic acid of which PCR is one of them. They wanted us to include the umbrella term, but we're more familiar with this, so that's what I'm using in my talk. So any DNA detection from an infant, defined under 12 months of age in urine, saliva, and cerebral spinal fluid, if it's found, sufficient to report a case and if there's a positive CMV antigen testing that would count to report. Not a lot of places that do that testing but the SMEs in our group wanted us to include that.

I don't know if we've seen that in Utah. Vital records reporting can happen if congenital cytomegalovirus is listed on the birth certificate as a prime cause or underlying cause or the infant death and then any sort of diagnosis that's found in the healthcare record in a child aged six years or younger and the reason we have that broad age category is because some things are not apparent. Some sequela not apparent until the child ages, so the diagnoses code, so if a diagnosis of a child under six years of infection, or 45-day old or younger infant if it contains a diagnosis of CMV disease.

These are the ICD codes. So cytomegaloviral disease is 25 point X.

So we did a huge survey with all the people I mentioned and first of all, we wanted to make this known. So symptomatic and asymptomatic, so if atypical hearing present that's sequela. So people started saying is asymptomatic with hearing differences and we wanted to make it easier, how about if we classify infection so no clinical signs whatsoever versus disease. And then we wanted them to rank, we had 23 different lab tests and results and also clinical signs

that we wanted them to rank.

The clinical signs how closely did they feel in line with congenital cytomegalovirus? Now there was a study done by our congenital cytomegalovirus team and they looked at 8 hundred 40 thousand infants across the United States, they found that many clinical signs were just as present in congenital cytomegalovirus infants as in noncongenital cytomegalovirus infants. Hard to see, liver disorders, they all were about the same, so not specific to congenital cytomegalovirus but they did find others that were specific to congenital cytomegalovirus.

So the signs that had the highest predictive value are intracranial classifications in the brain. Splenomegaly and PTI. What they did say had a low positive predictive value were liver disorders, hyperbilirubinemia.

So infant that has hepatomegaly, a rash is a clinical sign or if a child six years or younger that has microcephaly, cerebral palsy, and vision impairments that are contributed to congenital cytomegalovirus. The lab criteria we have confirmatory and presumptive. If confirmed laboratory evidence CMV detected in culture, or cerebral spinal fluid taken before 21 days of life. Presumptive laboratory evidence is anything collected on saliva only, up to 42 days of life or any of the previous ones I mentioned those specimens positive between days 22 and 42. So why allowing for the late testing, we had several experts adamant that they wanted a late test to count as presumptive, so that's what we did. These are predicated on negative CMV urine, so if comes back negative before 21 days the other tests would not count. That's considered the gold standard.

Then there's a classification table, it took us a long time to figure it out, basically we came up with three categories, confirmed infection, means the confirmatory laboratory evidence was present and no clinical signs, we call it CMV infection.

The congenital cytomegalovirus disease has two categories confirmed and probable, so for

either one of those the clinical signs need to be present. The O means one or more, the N means necessary. The difference between confirmed and probable is the timeline of testing, so if it's before 21 days of age on any sample other than saliva, it's a confirmed disease. If on saliva, or a late test day 22 to 42 days of life and clinical signs are present that's considered probable disease.

And we do have -- you can't see the whole table, but I'll show you at the end, we do say that if testing done in saliva, repeat testing should be done in urine. This is it in a nutshell in terms of case classifications in the position statement and the I want us to see if you're catching on. I want you to classify these cases for me, your choices are confirmed infection, confirmed disease and probable disease.

So case one the only information that is on this child, the only testing that's been done is there was an infant with a positive CMV PCR via urine before 21 days of life. What type of case is that? Confirmed infection. Exactly. You guy are good.

How about infant with positive CMV PCR in urine, 27 days of life and they have periventricular classifications with no known etiology. So page 27 on urine and -- that's right. Probable disease. If the urine was done on day 17 confirmed disease.

Two-week old infant with positive culture on cerebral spinal fluid. The diagnostic audiology exam showed sensorineural hearing loss. I'll reading your lips. Confirmed disease. Yes, exactly. Very good. Yes. How about a one week old infant with a positive CMV PCR via saliva. Nothing else. The only information we have. That's a tricky one. That's not a case. If that's all there is, not a case. How about an infant with positive saliva PCR at age 20 days born with hepatosplenomegaly. It's probable disease. The only testing was saliva.

How about six-week old infant with CMV detected in fluid. I'm seeing is head shakes. We know a confirmation of something to be confirmed disease, because amniotic fluid, we know it

happened before 21 days in utero. The last one positive CMV PCR, negative urine at day ten, thrombocytopenia, not a case. Because the negative urine trumps the positive saliva. I have a minute. I wanted to show you we reclassified all our cases in our registry and when we get a reclassification we ended up 135 cases. So there were ones done on saliva only particularly at the beginning of our mandate, because there weren't labs with positive urine testing, so even though continuing to watch them, we couldn't classify them because the only testing was on saliva that was positive. If you're interested in our cases, 53% so over half were confirmed disease and another 15% were probably disease, so 68% of the cases that we are confirmed or probable disease and just under a third were confirmed infection only.

These are all statement authors that I want to give a great thank you to and the rest of Utah CMV team, this is the QR code that will take to you the position statement. At any time, I don't know if we have -- two minutes for questions. Feel free to reach out, I'll do the best I can to help you.

Yeah? I love Florida.

>> I feel like I'm asking a difficult question, Florida is screening and hospitals are allowed to use saliva or urine, we are going to probably have to go through the same process you did because of the timing of us learning about the position statement and reclassify some of those cases. What did you do about the parents that were told that their child had CMV initially and then the cases were reclassified?

>>STEPHANIE BROWNING MCVICAR: Because it was just in the very, very beginning, how we had looked at those cases anyways and if they were positive and any clinical sequela, we counted them so we continued to follow them and we were lucky enough to have that longitudinal data to see -- we still don't know if they weren't positive. We don't know if that was right or not, so we didn't do anything, so, I mean, I never throw anything out, much to the

chagrin of my husband. So we continue to have a suspect list that we keep, a spreadsheet and we'll go in and check to see what's going on with that child. It won't officially fit into the position statement unless he fit the criteria and under six weeks of age.

A great question. I don't think you can make the statement that guess what, you don't, when we don't know that they truly don't, it's just that there's a risk of false positives and we continue to see it, even though we recommend waiting 2 hours after ingesting breast milk to do the sample, we get false positives on saliva. I know that's not helping. I'm sorry. So, yeah, I did take a picture of your poster, I'm excited to see it. I'm going to look later. I love learning from everybody. I've been told to stop.

Thank you so much. I appreciate you listening.

>> Welcome, everyone. I'm Jody Roberts. This is my team of support at the state of Minnesota. I'm so happy to introduce them. We have Gina Liverseed, Jesse Moen, Brenda. Look for the yellow karts.

>>GINA LIVERSEED: I'm Gina and part of my role is coordinating the long-term follow up for kids with congenital cytomegalovirus. So I'm here with my colleagues to highlight two collaborations that we have found helpful. To support our families who have been identified through our universal screening for congenital cytomegalovirus. So these are our objectives and we have our slides uploaded into the app, so we have three people speaking today and we'll all be here at the end to take your questions as well.

So to start off I wanted to give a little bit of background information on the legislation that we have in Minnesota that kind of guides our activities to address congenital cytomegalovirus as a public health issue. So our legislation is called the Vivian Act, passed at the end of legislative session in 2021. The first goal on Vivian Act addressed education and public awareness it directed Department of Health to make it available to the public and increase

awareness to the general public and healthcare providers. The second directive of the act addressed identification of kids born with congenital cytomegalovirus, so the directive sent CMV on heritable and congenital disorders, that expert committee reviewed CMV and recommended conclusion on newborn screening panel and commission of health accepted that recommendation in early 2022 and that was sent to the Department of Health to implement. Took us about a year to get ready to begin screening and screening of dried blood spots started February 6th on 2023.

This picture on the right-hand side of screen is of Vivian and her mom and brother. I just love her smile in this picture, that's how all of us felt we finally achieved this goal on beginning screening. So over our first year of screening, approximately 60 thousand newborns were screened and we identified infants with the CMV infection who are in or longitudinal program. All infants with a confirmed infection are recommended to have initial diagnostic evaluation that includes lab work, a dilated eye exam and diagnostic audiology exam. Out of the infants that completed that, 27% have had signs of bandwidth that might be associated with congenital cytomegalovirus and if you were here for Stephanie's talk she talked about long list of signs that can be associated with congenital cytomegalovirus. Many within this group the signs are nonspecific and some are transient, like lab values that we get one abnormal value and it's retested and comes back to normal, so this is a group of infants with the opportunity for long-term monitoring and intervention with all support professionals.

Out of this group we've identified 11 infants with congenital cytomegalovirus and sensorineural hearing loss some of whom have past initial newborn hearing screening. So really, the overall purpose of universal newborn screening for congenital cytomegalovirus is to identify the infection and any concerns as early as possible and offer interventions. Sounds like what we do for infants with hearing differences. We knew congenital cytomegalovirus was

going to be unique. We're the first state to do it. So we had a lot of conversation throughout implementation and planning. We agreed on long-term follow up infrastructure and figuring out what families need as follow up, so our considerations were what will be the experience of impacted families, what systems will they interact with, what supports are needed and how can we as public health support or facilitate those supports, so out of our conversations internally with our parent groups and with our community partners two important collaborations evolved and have emerged, that has been a collaboration with Minnesota incidence projects to increase the awareness and information that's provided to educational professionals, because in Minnesota CMV is a condition that's automatic qualifier for early intervention and we anticipated that this system would be interacting with a lot of to your families.

The second is the partnership with Minnesota Hands & Voices for partner outreach and support. I'm excited to have Jess and Brenda talk to you about their work.

>>JESS MOEN: My name is Jess Moen. We've been able to collaborate in reaching educational professionals as far as CMV outreach and awareness. I'm going to talk about three different ways that we did that in our education system to provide awareness, so the first way was our Department of Health as well as myself with the low incidence projects really targeted different groups that were already meeting on a basis in Minnesota and we went to those groups and provided information. Many of them were still virtual so we attended that way, but these are the groups that we were able to share information targeted at. So those are our early hearing statewide, educational audiologists that work this Minnesota wellness DeafBlind Community of Practice and Minnesota we have different regions in Minnesota and people in charge of facilitating that low incidence support, so that's our last group.

The second way that we shared information was really targeted to these people, so we have our early childhood special education staff and administrators that we wanted to target,

as well as those low incidence disability areas, specifically sensory loss and clinical and educational audiologists, so the next two things I'll share were with these people in mind that we were targeting.

So one thing that we did this year, we're currently still in the process of doing is a book study, we chose the book remedies for sorrow because it provided information about CMV as well as it provided a parent perspective that we were able to learn about.

So this book study is being done with early hearing detection and Statewide representatives, include audiologists, speech-language pathologists and teachers for the deaf and hard-of-hearing. So we're still in this process. We have one final session but we've had good feedback as a learning opportunity for this group of people and we're considering how it might be used with a broader audience. Gina is planning to use with public health representatives and we're excited to see how that might work. The slides are online where you can view our book study if that's helpful for you and take it adjust if you want that for your learning .

We had 45 participants that have completed so far in our book study and wanted to give you data, 97% said this has been effective use of my time for learn about CMV and the biggest next steps that people reported back were they wanted to share information about congenital cytomegalovirus with families and colleagues and want to be mindful of potential emotional impact that diagnosis might have on those families they're working with and learning more about the potential educational implications.

The third one I want to share with you that we did as far as awareness of congenital cytomegalovirus was a webinar series, a nice collaboration with Department of Health and Minnesota low incidence projects and DeafBlind project supported us in this work and we did a two part webinar series. The first one presented by Megan Pesch and she gave introduction

to CMV and what implications might be for children and families and second webinar was focusing on education and what are those impacts and how can educators support those children and families. So that was our series that we were able to present. The picture on this page is one of our colleagues that wasn't able to be here from Minnesota Hands & Voices and her daughter. Her daughter does have congenital cytomegalovirus and she was very integral in helping us develop our questions. With our webinar series we wanted to show you what we did before during and after. We had a nice multidisciplinary team that worked to put this together and we promoted it to the groups listed here. We targeted to early childhood leaders, related service, local public health, school nurses and audiologists. We have 2 hundred 70 participants attend our first webinar and 230 attend our second webinar and we were blown away.

We were excited about those numbers. After our webinar we recorded and linked to projects Web site and the web page so people can go to as a resource and utilize as made sense for them. From our webinar we have nice feedback from participants. 94% really agreed or strongly agreed they're understanding after attending the webinars and 92% agreed that the information is relevant to the work currently doing.

From the webinars we had a top four next steps that people were thinking about. One was how they were going to implement this into their day to daywork. They want to share information with family and friends, share with those that they work with, and then just seek out additional information. And now I'm going to pass over to my colleague, Brenda.

>>BRENDA HOMMERDING: Good morning. I'm the guide by your side manager. So I have the honor to work with these wonderful ladies and get the chance to work with Kelly. She couldn't be here today, but here's a picture of her. She has five children and her oldest daughter was born with congenital cytomegalovirus. So she is our hand guide providing CMV

parent outreach. Here's a flowchart of the system. We have a contract with department of health for deaf and hard-of-hearing cases it made sense we're part of CMV pilot program, so, basically, when a child is identified with symptomatic CMV, I go to the database take what I feed and we have it set up so that Callie can make the calls. I assign everything to Callie, she calls the family and reaches them and provides support, if she doesn't reach them she attempts to call them up. They reports that information back in our system and I take that information and report it back to MDH's system.

These next couple slides Callie put together and because we had a system in place we have a list of intake questions to help our parent guides facilitate conversations with families but certainly we let the family lead the discussion, but we tweaked it a little bit for CMV. So these are but the points of the discussion that Callie has with families. She talks about the child's well-being and development, support network, emotional health, she shares opportunities for the family to connect with other families. All the support groups on social media and she asks the families if they received the congenital cytomegalovirus parent booklet that MDH mails out. She offers to go over it with the family and answer questions they may have. She makes sure the family gets factual information from MDH and the web site and the national CMV foundation and certainly she can connect families to early intervention if not already connected.

And so over this past year Callie lumped this together, these are the topics that the parents want to discuss with her, they want to talk about the pregnancy and birth and what led up to it, the antiviral treatment is a big topic and previous screening and upcoming tests and vision screening and hearing screening. What the future looks like for the child and concerns about child care, breast feeding, future pregnancies, their emotional health and how they're handling the information and treatment and certainly the unknown an uncertainties of congenital

cytomegalovirus.

They talk about how to obtain mental health support while caring for a newborn and then of course the support or lack of support from family and friends. I'm a data person so I have to sneak this slide in, from this year's period of time we got a total of 38 referrals from the Department of Health and 27 were congenital cytomegalovirus only and 11 were congenital cytomegalovirus and sensorineural hearing loss. We had one child identified with hearing loss after the initial referral of CMV.

Out of those 38, 27 were reached by Callie and she made a total of 34 connected call us out of 139, so that means a couple of families had more than one connected call. She had one family that had in-person visit. I'm going to leave here with three things, one is I've been feeling so alone and isolated. My family doesn't understand. I didn't realize I needed to talk to someone that gets it.

The second quote is it was really scary in the beginning. Now I know about CMV and I told everyone I know about it. The last one is I spent so much time blaming myself. Thank you for reassuring me it's not my fault and I can't believe people don't know about this.

So, we're going to leave with questions. I think we have a few minutes for questions. I also will have the slide up here with all of our contact information so feel free to reach out to us at any time and then maybe to answer question you might have. Here's some information about our funding acknowledgments, so do we have questions for any one of us at this time?

There's a person back there. We'll get you a mic.

>> Hi thank you for this presentation. Super helpful. So I have a question for the babies who are testing positive for congenital cytomegalovirus but are symptomatic. Do you know if they recommend antiviral regardless. Some were told the baby tested positive but don't want to start antiviral before hearing test.

>> I have not seen any asymptomatic babies be started on any antiviral medication.

>> Hi, so I'm with Colorado board of screening, obviously one of the concerns is how we handle uncertainty with families with that CMV diagnosis but don't have symptoms for a while or ever, just wondering how the families that are on that journey are currently handling it, what are the perceptions of testing and if you have to push back along those lines or what we can expect as we look at this ourselves.

>> That's been one of the challenges. For our pilot we had to define a population that would be manageable with the capacity of Hands & Voices, so we picked this line of symptomatic. We know that's an artificial label sometimes we're putting on kids. I do know that some of families that I kind of said well you have a symptom because I had my list of criteria last wide and we did refer to Hands & Voices. Still appreciated the support. One of the quotes that was shared it was scary in the beginning, now I know everything is fine, that's a baby classified as asymptomatic. So we haven't had opportunity to reach out a lot, we have a grant right now that we're working on that will allow us to reach out to hopefully a larger amount of people to understand those experiences a little bit better.

>> Thank you. I was wondering because our state has not implemented CMV testing yet, but we have hospitals that are doing the testing. Do you have your information available on the Web site so I can refer them to that?

>> Which specific about? About reporting.

>> Kind of in general, so my infectious disease person epidemiologist checks out everything, so...

>> I can get that to you. I should have put our Web site up there, either by my e-mail or I can get you our Web site, too, and we'll have our -- CMV is up for addition to our infectious disease

reporting rule as well, going through the process hopeful it's to our governor and happening in our state too.

>> I got your e-mail, so I'll e-mail you.

>> Okay.

>> I have a question and comment, the webinars that you mentioned earlier, are they available to anyone of your Web site or just specifically Minnesota?

>> Yes, they are available. Anybody can view them on our Minnesota low incidence projects web page linked in the slides. Anybody can view them. Our second webinar includes a lot of stories directly from parents in Minnesota who have children who have been diagnosed which is nice to hear that perspective as well.

>> So this is my comment, I feel like I'm preaching to the choir about this, in Florida we're embedded with newborn screening and the newborn screening follow up does look different than the hearing follow up. Hearing follow up happens much more long-term, the newborn screening follow up and in our state newborn screening doesn't really reach out to the parents specifically. They refer parents and those referral centers reach out to the parents. I feel like there's a gap. We are letting parents know their babies are positive for CMV and they're asymptomatic and they're not getting follow up. As a parent, if I was told that my child had CMV and I did not get any contact from another parent like what y'all have described, some of those quotes about feeling isolated and alone, those parents are following that, so just a comment. I think we need to figure out what to do about this gap.

>> We're out of time.

>> Please clap. They're amazing. Team Minnesota, everyone. They're awesome. I have to classify something, I gave a poor answer, she asked because of our classifications does the parent told no longer have CMV infection. The position statement is for public health

surveillance. Those are case classifications for surveillance, not intended for clinical care or use. So even though we're classifying the case in this way, it doesn't change what happened in the clinical arena, so I apologize. I had to clarify that, or I wouldn't sleep tonight. Thank you.

Don't Forget the Fun: Turning Real Life Events Into Powerful Learning Field Trips.
(Captioner Standing By).

>> Hello, welcome, everybody. We have 30 seconds to start. My name Tara Nikou. This is Mary Ann Stefko. We both cover the state of Pennsylvania doing birth to three services. I'm from the southwest part of Pennsylvania and she's diagonal in the northeast part of Pennsylvania, so we cover the 2nd corners of the state very well. Our presentation is don't forget the fun. We in early intervention when we're working with families from birth to three get the heavy part first, when families are newly diagnosed they focus on the medical part of the journey. Do I need hearing aids, do I have to apply for SSI and medical assistance. It's heavy at the beginning.

As early education providers we recognize that, but we want them to remember this precious anything in their hands is a baby first. Hearing loss comes later, baby first. Because working on heavy things, now I have to keep this on the baby's head, they keep pulling it out. We remember that all babies put anything they can put in their hands in their mouth. Now there's this material, naturally goes into the mouth. Of course it's going to go into the mouth. So we prevent -- whatever we are, our teachers going in and remind them it's all typical normal development, so we want them to remember the fun part of being a parent.

Yes we recognize every child has challenges. So we remind them how much they are a typical family doing open to milestones. They've teething them, they used to sleep, now they don't. They don't feel that because they're going through the grieving process and something

different about their child, so us as teachers going in and says, yep, this is what happens. They're going to suck on the hearing aid because it's there. BAHA babies don't want to wear it. It becomes a game of fetch for mom. That was fun I'm going to do it again. Especially at the playground and mulch on the ground. Fun, fun game for babies.

How many parents in the room, parents of deaf and hard-of-hearing children. I'm sorry. Bad Tara. How many professionals do we have in the room? Okay. Look at you. Thanks for coming. We welcome you to our slide show, now to have the fun start. Here's Maryann.

>>MARY ANN STEFKO: Hi I'm a teacher of the deaf for 38 years. It is a journey that I love. I love my babies, I love my families and I would not have done one thing differently. When I went to college back in the day, I heard deaf education, you're never going to find a job. Deaf education it's the same every day. I'm here to tell you no two days of mine are ever the same. That's so awesome for me top so thank you for being here. I'm going to disclose right off the bat, there will be no statistics, no research, this is all Maryann having fun with her babies. Thank you for that. I don't want to mislead you but I do want to share the fun I have with my families. Some of them are in the room today and I'm grateful for their support.

I'm going to show you some cute babies up here in a little while. I do want to talk about a couple of things as we get started and those are the objectives for today, so we're going to be able to define the parallels between family activities and how they can be powerful learning opportunities. We are going to be able to identify ways to incorporate technology and use them in real world settings even with our youngest littles and I'm going to tell you that what Tara said is true, all of my families say the same thing with the first hearing aid. I can't keep it on. We lost it.

Over Christmas a mom and I went shopping to the local grocery store and guess what happened? It get put on a shelf behind the ketchup. Those things happen but we hopefully

have come up with ideas that might help you encourage that technology use and make it a little more comfortable and let me just say I'm here to tell you while hearing loss and deafness has been a part of my life all my life, not my family, not my experience as a parent, but I know it's hard when you get that technology, right?

Often I have families say Maryann I don't want to wear it when we go out. If we can work together and they learn to wear either at home and you don't have to worry about those other things it makes wearing it out easier. Finally, participants will identify coaching tips to share with caregivers and other family members, that's a big selling point for me, other family members to expand opportunities for learning in practice, so in the state of Pennsylvania we are rolling out a coaching model of service delivery. That's not presentation for another time. It doesn't mean no direct teaching, it's about empowering our parents and caregivers. When I got into this field 38 years ago, people would say to me, Maryann he'll do it for you. Those aren't compliments.

They really aren't. One of the nicest things parents can say to me is Maryann, we don't need you here, we want you here. I give him the tools. It's great to be wanted and to be back, right? So coaching in Pennsylvania for us is a huge initiative. It's definitely changed from traditionally the way I was taught to teach deaf children and their families to coach families of deaf children and let them see the growth and gain. Isn't that a wonderful opportunity, right? When I went in once a week, once a month, that was all the time that child got to practice that skill.

Now they get it every day, all day long and because of that this presentation was born. One mom said to me at Christmastime, she said to me, you know what Maryann, it's not my job anymore. It's fun for our family. Think about it. Most of your deaf and hard-of-hearing kiddos are used to the medical model of intervention, right? Which is clinician, child, they say

the in front of each other and that really doesn't include any other family members. You're going to see in a little bit everybody gets included. I walk into the house it's all skate. I actually had the lady who cuts the other sibling's hair join us one time because she was there to confirm an appointment, so you never know who you'll find or impact.

Let's talk about opportunities for fun at home. This is what it starts. This is where parents can A learn. You don't want to learn with me when you're out in fact community. You want to have fun with me. I want you to learn the signs that you're really nervous because you tell me you're not an interpreter and you'll never be able to do it, right? When you learn in a routine it's more powerful.

So let's talk about doing the dishes, right? You want the child you're working with to wear hearing aid and respond to sound. How much more fun turning that water on and off and having them sign water and how much fun to add that dawn dish washing soap and what happens? Yeah, bubbles, right? So now we've gone from oh, let's listen to that water, to bubbles. The bubbles go up and then what happens? They pop.

Right? So, again, simply washing the dishes can be so super, super powerful. Think of the language with that. And you can do that no matter where the child is, right? I had a mom not too long ago whose little one was running around the kitchen and her job to stop when the water went on and off. Maryann it takes me an hour to do the dishes now but it's so much fun because we do it together. And guess what grandma can do it when she comes over. How fun is that? How much time do we spend as families together when people aren't connected to deaf and hard-of-hearing kiddo. Doesn't take a lot of language to turn the water on and off and make bubbles and go from dish to washing the car.

You have two options now. Guess what you can do? Go to the car wash and spritz that car down or take it through the car wash or do it in the front yard and boy can I make bubbles

in pails of water and then put the sponge in and guess what, all the siblings can help. I think I've had neighbor kids come over. Are you guys washing the car? Yeah. That doesn't make my deaf and hard-of-hearing kiddo that I'm their to teach any different than any other kid who's come over to what about the car. Look at that.

And isn't that what it's all about. Not about me then. Guess what, my little friend their older siblings say do you know the sign for bubbles, I go show them and she sign bubbles and they're so proud. It's not anything that you could easily implement. And not anything that won't have a huge impact on the siblings and neighbor kids. We want our kids to be included in everything, everything.

Okay. Here is my next favorite. Doing the laundry. I'm not suggesting, at all, that they put the soap in and make bubbles. No. But I am suggesting that even the littlest ones, so I have a little group at school that comes together every other week and we did this as a large group, because in coaching some of the time the challenge can be Maryann I see them as day care, what can I do with day care, right? So that's why I put this in here. I do in, in a group and I've done it at day care. How much fun is this? I don't do the laundry at day care but I want you to listen to this. Now, this is Maryann old school technology because I don't have WiFi and I didn't think I could do this.

(Music playing)

>>MARY ANN STEFKO: And that's enough, because you'll be seeing that song all day long courtesy of me. It will be stuck in your head. My mom said I use this, it's been a month and we're singing the sock song. How many socks when you have kids do you wash every week, right? What happens? Either before you wash it, you can do this and it incorporates singing and dancing and it's fun, right? They have a really good time with that. How many times do

you lose a sock? I don't know where my socks go. I really don't. And so then after you wash them and 10 minutes already? For heavens sake. When you wash you have to match up again and it's counting and numbers and singing and dancing. I tell moms and dads and grandmas and grandpas, stop the music. See if they're newly implanted and can hear that, the music stopped where did it go.

Sign sock, sign purple, sign yellow. You don't have to have interpreter to do that. Anybody there can do all those things. Singing and dancing. I'll take that out we've done that and it's still in your head. I know. Yard work. This is how I try to encourage my parents to get that technology on outside of the house and they all say to me Maryann they've going to lose it. Okay but if they do lose it, it's in your yard and chances are, I don't know if they're going to lose it, because they're not going to fiddle with it. When we ask them to collect leaves or look for bugs, right?

They could be so into doing those things they're not going to care that it's on. April, ants, see the connection. You can find lots of bugs in April and you catch the bugs and you have all that fun time. What do you need? You need the sign for bug. Let me tell you every time you're digging around out there you sign bug, ant. All signs we can teach parents, ideas to do them you put them to use immediately and not only parents, siblings, neighbors, right?

I've had whole little streets who've made bug catchers and they love them. You find fireflies whatever you call them and it expands so much language. No cost. Here's any other thing, no cost. And that's important to me, because I have some families whose resources are limited. And I absolutely encourage them to purchase this or do that, but there's so much you can do that's just at home. Moving along Tara.

Out in the community, so when you've got that hurdle done, wearing that technology through all these fun thing you're doing, you take it to the community. Again, no cost. Use

what's there. The local library typically has a story time and typically 30 minutes for our birth to three little birth. Parents have felt super empowered, we kept it on two days this week me library, 30 minutes each time. Better than not keeping it on at all and in that taking with you. That's huge.

State parks when you get crazy take at that bug experience and go to the park. See how many more leaves you find and see how many different bugs. Be careful. We don't want you to look for something you shouldn't. The grocery store, typically there's so much to see and hear and smell at the grocery store, right? When they're smelling at the bakery, no one is pulling hearing aid off, I can tell you that. We do it every week.

Every single week. Recently one of my moms said I don't go to the store anymore. I do curbside pickup. Great bring that bag, bring everything out and put it on the count and shelf. She chuckled, I knew I shouldn't have told you that.

How many have in those play kitchens, it's all right there. You don't have to buy or do anything, you brought the groceries anyway. Thing of the language growth you can do with that and you take that into cooking and any of all you can do. Huge, huge, important change. Tara is going to add.

>>TARA NIKOU: So in Pittsburgh, when you get to the bakery counter you get a free cookie. Your local grocery store has one of those things, every time you go to the deli counter you get a piece of cheese. So there are free things you can get from the store.

>>MARY ANN STEFKO: Thank you Tara. I really want to make sure I highlight this, this is really convenient, if you use the Hands & Voices tip sheets. I have nothing to do with Hands & Voices, total disclosure. Hands & Voices has awesome tip sheets, if you look at the last thing there's something called a family activity plan, right? I use it all the time with my families and guess what it says one of the little cubes says a fun activity I can do.

So, use that. Use that if you're a parent download that and use it. If you're a provider a great way to gather information as to what's happening with the family and it's free and it's a resource that Hands & Voices created just for our little people, right? Why wouldn't you use it? Looks at literacy, language and social emotional development, the thing I talked about today crosses over into all of those. I recently said to a mom I work with, put it in a notebook. Wouldn't it be fun to see how far she's come and how much she's grown and what you've been able to do with her as a family.

The other piece that's worked well for me is using that family activity sheet and grandma can write on it. What happened when you were baby-sitting this weekend. How does that make grandma feel? I did it with her and him. Those things are so important to make those connections. I'm not giving families a list of 20 signs. I'm not giving families a list of three listening gains that they have to do four times a day. I'm not doing that, right? I'm embedding all this in what do you want to do, what do you do naturally in your family that we could get the most bang for our buck and have an amazingly good time.

What those kids are going to remember, nobody says Maryann I'm able to identify the presence and absence of sound, but so many kids point to the water and go -- descriptive sound -- or point and sign water in their little hands. Isn't that awesome? That's what we really, really want. So please, please take some of these ideas, take what works throw out what doesn't and think outside the box, right?

We have so many opportunities to enjoy our kids. I'm going to tell you like Tara started out with, I get it. I've done this journey for a lot of families. The appointments are heavy, the doctor appointments are heavy, what you have to do on the list of things is heavy, right? We have to bring some joy back and have to excite families about this little human that's in front on them and she them what they can do, handing them a signed book with 5 hundred signs

and five grammatical structures. Folks aren't going to read it. Not fun.

But let me tell you what, teach bug, teach sock and be able to find and have it and run around the room and find the matching one all while listening to cocoa melon, so much fun. I'll leave you with this. This did not go as planned. Total disclosure. I said find me something green. What was I thinking as a teacher? Grass. We picked a zucchini. So I taught zucchini that day and we laughed about it. The local strawberry patch, right? Families take their kids there all the time. Absolutely. Next one, I have 30 seconds left. Rolling down the hill. Daddy loves to golf. Look at all these things, right? And any two little friends me local carnival, all we wanted was wee and we got it. We had it. And then look at all these cuties, talk about what you can do with grandma and what you see at Halloween. I can't believe he let her dress her up that way and she stayed that way for a while. She said we're working on the sign or red.

Got a lot of mile out of it. Those are the things that are super, super important, so if I can answer my questions. I know I'm out of time. If I can answer questions, I'll be back there, we'll be somewhere, just try one or 2 things and I hope it goes as well for you as it does for me. I would play the cocoa melon song, but I won't. Have a good afternoon everybody.

Nature as interventionist: An experiential guide to learning.

(Captioner Standing By)

>> We'll be starting at 11:30, but I do have a room key left over in the last session, so for a good time, go to -- I won't share it. Remember the evaluations are in the app and our presenters love your feedback. Thank you.

>> Welcome, everybody. I'm Jess Dahlman. I'll presenting on nature as experiential. I'm a facilitated psychotherapist. I used to live in this area and work with people here but I live in Wisconsin now today I am presenting on the role of nature in supporting all sorts of development things.

So that's me. We present NBC a year and a half ago, I saw that stick. I was like that's the coolest stick ever. There's at least four different species of things growing off that one stick. I got excited and fascinated. I wanted to picture of it. That was part of the point that so many ways nature inspires curiosity and awe and it inspires communication. I wanted to know the names for those things and I wanted to talk about those things with the people with me.

So I'm going to talk about a few different things but mostly we're going to look at pictures and I hopefully will give you a couple opportunities to engage with nature objects up here. If you happened to read the abstract I mentioned data around the role of nature in supporting development.

One of the first books that came out was called the last child in the woods. It focuses on this theory that a lot of ADHD restlessness are related to deficits in our development. We need deaf perception experiences and we need fresh air. There are other books out there and more and more research is happening. A lot of research comes out of Japan. You might have heard of forest hunting, but if you want to learn the science it's out there.

So the first thing with this concept of nature as interventionist that I want to highlight is the role of diversity. So many ways kids dealing with development identity, self-esteem, they want to fit in or match or want to -- but so much about mental health as we grow older is about knowing who I am. I'm unique and there can be similarities but the differences is part of what makes the landscape really spectacular, so one of the most simple interventions is to explore the diversity and differences in trees.

That can happen at a young age through touch and texture and smell, but it can also happen at later development ages too. One of the things we know happens with trees that people get curious about the differences, instead of being like oh, that's weird. I don't know that I ever heard somebody say that's weird about a tree. It helps us break out of judgment

patterns that are associated with difference and build that resilience from a really young age.

It can be important for parents and caregivers as well to really engage with like that tree is okay as it is. That tree has a role in this ecosystem. The next thing I want to talk about is community-based practice. That nature has a way of bringing us together, so in this particular the big picture up there was a collaboration with multiple different organizations in our community and we planted a healing garden, it was several different groups and we did art projects and helped them engage from a sensory based perspective. These were older kids but a good portion had never planted a plant. They didn't know how to get the roots to breathe and know how deep to dig a hole. So planting seeds, transplanting plants, there's a process of developing self-esteem and competency and, again, a sense of connection that one of the biggest metaphors is that interconnectedness. I wonder how they're connected underground.

One of the things that Richard talks about in his research is the role of nature specifically with autism and theory of mind. Animals have a way of working beyond words. They help us take perspective, so when I was here in Colorado, I don't know if any attended the deaf autism that happened yesterday. I was part of getting that off the ground. That first picture with the kiddo next to the cat. The kid couldn't make eye contact with anyone. He saw the cat and looked at the cat, looked at the cat and shared the view with the cat. A beautiful moment of, like, a glimpse of theory on mind.

Then there was another opportunity to communication. People could engage with him this they weren't having shared interest or shared spontaneous communication. I do find that a lot of kids who feel that they are different or struggle with language from different ways aggravate to the cats and chickens, even though I'm like horses, so great, but something about working with the nervous system of a cat or chicken that can support awareness of breath, awareness of pace, awareness of consent. Is the chicken saying you can touch it now or running away

from you.

It does connect back to parent coaching and parent support. Even when there isn't comprehensive verbal experiences so much rich information and communication in the body language and we can break out of very human obsession of words and get back to body language and what's actually being expressed here so caregivers and kids can connect, on a nervous system level.

One of the newer pieces of research is about the role of FracTELS, they have a way, that pattern has a way of soothing the human nervous system. So whether a coloring page of this or literally the ones looking up close a pinecone is in a FracTEL.

It's soothing for kids that feel the world isn't predictable for them. They don't if they're going to be understood, or hear or understand in certain environments, so the predictability in attuning to nature from this perspective is useful. There's math in this. There's science in this. If they're like oh, pretty, how far can you go with that ? It's natural, spontaneous language based off of what they're interested in.

I will also say most of those I got off the Internet but the one on the left is golden mushrooms. I'm a mushroom fanatic. The process for mushroom is underground. The mushrooms we see are the fruiting body and again there's so much metaphor there for working with the kids and the populations we work with. Whether you're a provider, there's so much going on under the surface. You have no idea what it took for them to get there that day and no idea what other layers are going. The roots run deep like April said. There's ways of letting people show you what they're interested in and growing out of that together.

This one is coming back to awe and interest and curiosity. The first two pictures there are a natural phenomenon that I never experienced until this winter, so I had to put it in this presentation. I don't know the name for this phenomenon but these little icicles were 2 to 3

inches and grew up spontaneously in the woods and they were crunchy a beautiful texture experience and they were FRACTELS, repeated a femoral short-term experience. So even though I go to this place over and over, it's a place to go over and over and over it feels like it's the same language and tree and feel, but different times of year and different circumstances still ask surprise us.

Having that open mind and readiness for something new to emerge can support both kids and families and providers and leaders and administration. I'm a horse person, so here's horses at the facility we have in a group. So much of nature and horses is about coregulation. About having a reliable nervous system that says this is okay right now.

Whether sitting next to a tree and feeling a gentle breeze and being like I don't have to do all the work right now, or whether it's grooming and having a rhythm a physical movement rhythm or whether it's literally kind of laying on ponies and giving hugs. This pony is pickles and she loves hugs. So this client spends 30 minutes in that position most of the time.

So a big part of what is missing in the early intervention world in the deaf Ed world is really about regulation. If you can be here present and supportive, then your relationship will help you get through whatever five years from now and nature and horses model that over and over and over. It's simple but not easy. The rest of work world, even EHDI conference is so fast, it's go and do and plan and think ahead. Nature has a different rhythm. Nature has a way of doing okay, this is what it is. We can just connect. Turn us out that just connecting is so much more than planning and doing, especially for kids feeling stressed or disconnected or parents feeling like they're constantly fighting the system.

There's feedback saying this isn't safe or predictable or reliable, but there are places to go to support these families or support us and there's other ways to do this. There's other ways to do this. I think most of you should have gotten the handout a resource for y'all. I'm going to

bring these hand outs to the self-care table if you're interested in chatting more. I forgot to change the title. That's supposed to say parallel process. So one of the things not infant mental health field is really this reinforcement of coregulation, newborns, infants, young humans are wired to look to nervous systems to figure out if the world is safe or not. If you're worried about the next day and trying to put a newborn to sleep that baby will not sleep, right? But if you're like oh, I'm okay, I'm tired too, no problem. Baby is asleep. They reference us.

When we talk about infant mental health as a field, the concept is as providers and mentors, we learn how to holding ourselves and support our own nervous systems so we're a reliable reference point like nature but there's a stillness a calm there's a predictability. And as we do that for ourselves, we can support the parents and caregivers so they can go I can find that stillness. I feel held by other parent guides or deaf mentors and hold myself and now I have the space to hold by baby even if my baby is colicky or tearing things off the wall. I have a reference point for life being okay.

But outside of that chain reaction is our community and society and world and in so many ways, depending on your background and cultural experiences, there's so many messages that say deaf is not okay or different is not okay but you have to fight all the time for these rights for accessibility, right? That's not soothing. That's not soothing.

So if our reference points with mainstream schools or reference point with mainstream government systems not soothing or not predictable, then we as a community need to go back to nature. Because there still is a reference point for helping us find our calm. And those babies can't find their own calling without us finding our calm. It turns out that it's really hard to learn if you're in this regulated state, whether rushing from session to session and now I don't remember what happened on Monday. Was Monday yesterday? I'm not sure. The same thing for kids the faster we go, the less likely we are to actually remember, but our bodies

remember that urgency and that stress or our bodies remember that sense of calm and permission and acceptance. I don't have very many reference points outside of that. Nature has a way of bringing us back.

With horses, you know, we literally get to explore the Metphores of leadership, whether family leadership or systems leadership, that often when we have to get something done we pull. Horses say that's not cool. They'll literally dig in their he will heels. I worked with people just calming down and the difference between gripping a rope and holding a rope, right?

You can see in that first picture when practicing that amount of pressure difference is felt by a horse and that amount of pressure difference is felt by a kid. They always know when we've had a fight with a partner. If we can practice with horses it doesn't feel so personal or I'm bad or wrong or should have known this sooner. I have so much muscle memory doing this and when I get a place where I can practice having this muscle memory horses just come in. I don't have to use the rope for them to follow me. That's cool. Kids are similar. When present and connected, thinking I want to be with you. I work with families all the time, so fun to see kids show interest in who parents are, caregivers are as people. They're like wait I thought I just provided you food. You want to know what it was like for me if kindergarten?

Oh, okay. I'm a human too with you. That's way more fun and spontaneous language again. One of the biggest things about nature for me as intervention is that you can love whatever you love in nature. You can love the trees and mountains and water, but there's an indifference. It's not about loving -- the love doesn't change the mountain or tree necessarily, but it changes you. In that process, if you love something, if you lovebugs or mushrooms like I do or love water systems and interested in how water moves through the world, you pay attention to it.

The more you pay attention to it you build awareness. Oh, these parts are all connected,

okay. And the more awareness you give. The more you can actually attune and predict the weather and the cycle of the water or the rhythms of the water and the more you attune, the more you feel attached, like I am connected to the water. The water literally keeps me alive. I can be part of keeping the waters healthy. There's a reciprocal relationship beyond love, when we pay attention it builds awareness and attunement and attachment. So nature showing us a pathway, how can we help families?

So when families come in and go I don't know how to -- right? How do we get them to pay attention. First pay attention to the baby. Just like nature gives us lots of information even without words or shared language there's information there that can build awareness. I've paid attention enough to have some awareness of this is how my baby likes to be held or this is how my baby likes to be fed. That's awareness. As that awareness builds and that confidence builds like learning how to plant and tend to a garden, that attunement is there. Oh, you're about to get hangry, what if I feed you before the hangry. Like we can predict the seasons, but it takes time. This builds over time so we can normalize just like time is part of seasons and you can't dig up a seed and expect a fruit. To some agree five years doesn't matter, what matters is right now and using nature and engagement with relationship with nature to enhance that attunement process, so they can attach to whoever this kid is. The kid will show you who they are just like nature reveals itself. So I'm out of time. Am I out of time? I have one minute. Cool. Any questions?

>> Thank you so much. That was really interesting. I was wondering for like the people we serve or ourselves in urban centers, cities that don't have access, like Denver has access to natural wonders. Do you have any suggestions for us?

>> Nature is everywhere. Plants are growing out of cracks. There's numerous people who teach urban urbanism and walking through and noticing the weeds and teaching you what's

edible. It's accessible everywhere just a different type of immersion and bringing this inside the home. I have a comment about the role of pets in supporting the nervous system or having plants inside. Some of interesting role with hospitals if you have a flowering plant indoors it supports immune system function and biophysiological resilience. I'm out of time. Enjoy lunch. Thank you, everybody.

END TIME: 11:56 AM