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EDHI Mineral Room BC A Decade of Progress and Challenges: The Mich...

(9:40 AM - 10:05 AM)

Newborn Hearing Screening: Collaborating with...

(10:10 AM - 10:35 AM

 3/19/2024 11:10 AM, EST

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(Captions provided by a live Captioner.)

»  Is it 9:40? Go ahead? Are the. All right. Thank you for coming. Hello, everyone. We're going do get started. I'm going to take you on a super quick journey of the Michigan program, the for the 13 years and spearheaded this project over ten years ago, so these are the learning objectives I'm not going to spend any time on this. I'll give you a minute to read them.

So I wear three hats. In this project this overlap. So one I'm the EHDI program consultant and unofficial midwife liaison and also the Eddie coalition for the Michigan coalition of deaf and hard of hearing people and correlate with EHDI and midwife trainings and stuff, and also stuff machine, and package and sell supplies and holder of the travel machines and ship them out as need and the coalition decides on the placement of the machine using EHDI pat.

So why did we pick the coalition to do this project?

So when we wanted to look for grant funding, you needed to be a 501 C 3 which EHDI was not, and the Midwives were not. We need an agency to be able to handle all that. And we initially approached the Midwives themselves, their own association and we were working on licensure at that time and didn't feel they are the time or energy to do this. And when I talked to other Midwives, that were not part of the Michigan association, they were afraid they didn't have control and you couldn't get membership unless you were not able to get a machine unless you were a member of that, so the coalition as neutral ground worked really well. The coalition owned the machines, insurance, machine upkeep, so the cables are a couple thousand dollars. Replacing batteries, chargers, all of that.

So the midwife fees pay for NA. So this is the timeline.

So 2013 we actually wrote the grant and awarded it late in 13. And we had a choice of ABR, or OAE, and ABB was chosen and homebirths would not have to go to the hospital as much and in 14 we —— the teams and had participation. In 2023 we purchased two different types of machines to try to test and trial out and stuff. So right now we have a total of 28 machines. That are distributed to the Michigan Midwives.

So when we wrote the grant, we knew nothing about where the Midwives, or in Michigan with the homebirths were, so the picture on the far left is where we proposed to put the first machines.  Looks right, right? And in 16, when we got 16 machines, that's where the populations and Midwives, and home populations were happening with two travel machines. And now with 28, the far left it's harder to see because the dots are overlapping, but 23 were placed.

It's important to put the machines, every midwife would like their own machine, of the course, but not practical because of the insurance and collaboration, I cannot afford to do this project with 70, 80 machines, right?

And the machines are cost effective, each machine is screening a minimum of 40 to 50 babies a year. So when I do placement, I want to assure at least one a if I can. During COVID, the machines were kept where they were and did I want do EHDI analysis because of convenience.

So a few COVID was wrapping up, I had a midwife pushing for a third machine in your community, but when I got the EHDI data, turned out all the Midwives didn't need three machines, so I have one stay and one move to a more accessible place so people doesn't have to drive 30 minutes just you to get the machine, so it stays now in a better place. I talked 3 months of that, and people aren't saying go get that machine. Go get that machine. So placement is really, really important.

So of the challenges we were coming across during this time, Midwives licensures, machine glitches, cost and of course the COVID pandemic.

So we'll go through each of those. The, The 2017 was the professional licensing of midwife and because of licensing, more became interested in providing hearing screening for the first time and we knew that was coming, remember we bought ten machines the year prior, so we learned Midwives doing it under a screening grant were doing it with practice, and we were getting them connected and doing it as part of that.

We also found on January 5th, the CCHD, and EHDI, I ongoing training needed to be cut because I had new student Midwives coming in, familiar with the machine and all of this, and we were questioning why they had the buy the supplies from the coalition when it was much cheaper to buy it from the supply thing.

So I explained yes, you are required to buy them, but if you buy the machine you have to buy the supplies to get it going, so House Bill 5482 of 2007 was passed, it said healthcare professionals, and in 2019 when the Midwives licensure was passed, so any provider can have screened and educate the mom on that, and within 30 days is part of the goal. And reporting is part of that law, so screening under 12 months of age were to be diagnosed by EHDI and anyone under 3 years, by a license audiologist of course had to report to EHDI.

And within a year or two, they were sold again and the supplies for the supplies with each acquisition got costlier, and the electrodes used to be 200, and they wouldn't last but a few months, well, we were doing that many maybes this in period, so we had to look for supplies for the electrodes that they were not for that specific brand. And the ear tips were getting costlier, and they fit but was not associated with that.

And the tubing went down $2600 batteries that were ten dollars went up to $60.

It was just crazy, so I found other sources I no longer buy the battery for the machine, I buy a generic one from Amazon, so we are not buying any of the supplies from the vendor that the machine originally came with.

» Urgently, in 2015 we started have machine glitching. And anytime you, you have new Midwives, it is training, but it turned out it was the machine's problem two had to be sent to Denmark for refurbishing, and two need software updates and it took years, so we used the travel machines a lot to facilitate this.

So now we're testing new machines, which is what I was talking about, the last two machines are from a totally different company called Q screeners but use the same electrodes, so that was interesting.

During COVID, Midwives demand tripled, people didn't want babies in the hospital around COVID germs.

So we suddenly had to get more supplies and find another electrode, we couldn't replace it at all and had to go to another one. Now, COVID impacted the Michigan Midwives Coalition, and we had to get a calibrator and redistribute them after the calibration. So the machines we're freaking out and wanting to be calibrated and one of them couldn't work and we ended up shipping it to the collaborators and I didn't trust the post off the at that time, because they were dismantling systems at that time, so the vendor agreed to go there in the meantime, and that worked out really well, the midwives had the ones within 15 minutes of him getting there.

But the further ones we shipped. We got back into training and ended up doing a training at the Amish birth is center. We begged for years, but it's such an inconvenient location but we got all these midwives complaining, I said yeah, try going on horse and buggy.

[Laughter]

Then they shut up.

[Laughter]

2022, we went back to the normal stuff. I apologize for the small front, I wanted you to read it side by side. We started the program in ‘14, first full—year data ‘15, ‘16, and comparison to 2021. So we can get there. This is the meat of the presentation; we could not get this without the machine and the midwives. Shout out to them, in—house went from 577 more than double to over a thousand births, I'm talking hearing screening increased to 86%. Access midwives, they can call me and I can ship the machine, their numbers stayed similar, 500 births a year about and screening went from 52 to 62%, education midwives. are highly educated on the EHDI process but don't have access to host or a travel machine, their numbers increased by 2.5 times and their screening rate dropped we half but the initial group of high education midwives. Closed in 2017, so they did not continue that.

And for whatever reason, decided to refer them out. And lastly, the non—participating midwives, cohort, went down nearly 2—3rds from 1356 births to 576. But their screening rates went up from 14, to 23% so that was even higher than our 19% when did when I first started the program and not having the machine.

So looking at the data from the previous slide, it's easy to think if every midwife had a hearing screen, the majority would get a hearing screening, with 86% in '21. However, this is not the case and has host rate factors, a lot of work goes into getting the higher numbers and machine removal is sometimes done by the midwives, who are they are not using it. This is very much a business model, if we don't get money on that, the program will not condition.

Real quick I'm going to give you a ——

»  My pregnancy with Lucy went smoothly, the first went really well. You know, it was just like any other birth, it was painful but productive and I didn't take very long to have her. I don't remember how many hours it was. But it was nothing out of the ordinary. When she was born, I remember one of the midwives, saying look at her perfect little years. They're just so tiny and perfect. Which is kind of ironic.

[Laughter]

Since they didn't work. But everything really went well, for the birth. It was, I had absolutely no idea that anything would possibly be wrong. I think they came back the next day. The day after she was born, or possibly it was I think I had her in the middle of the night, so they came back the next morning. And I believe that's the first hearing test they did. And she didn't pass it. But when I had Sawer, he did a hearing test on time, and I don't know why sometimes it takes longer. I thought oh, she's fine. It took a long time for him and so they left and said well, we'll test her again text time.

So they came back, I don't know a week later, and a different midwife tested her and only gave it five minute and I thought well, she didn't give her enough time it just didn't work. We went for the 6—week visit to the midwife's house and did the test for a long time. Obviously, she still didn't pass. And she said well, I think maybe I'm going to refer you and you need to get her tested. She was six—months old. She had hearing aides at this point. She was six—months old. And they said well, we show nothing coming up.

And I thought this one's probably wrong and we decided to go to UMM and I went to the booth test, and they had me wear ear plugs. And it was so loud in there. And she did not respond to anything. And I'm, like, okay, I believe them.

»  So at three and a half she is doing amazing because I had so many people backing us up and thing along the way, basically we're in the basically community, her communication is awesome, she's in the deaf program and our county for signing is so good, she understands everything, knows her colors and numbers, and sign what she wants and signing in sentences. You'll say oh, she's deaf and people will be like awww, no, we love it. It's awesome. It has brought us into a different world, different perspective, I would have never met these people who are awesome. I wouldn't know any of this. It's learning a new language, a new culture. It's amazing. If we had not had the newborn screening, who knows how long it would have taken to realize she was deaf? I mean, I heard about people not knowing their kid is deaf until 2 or 3 and can't talk or different things like that. But if we had waited two—years they, she would not be anywhere near where she is right now. Her communication, she would be just starting to learn basics. I think it is super important to learn right away. This is when the brain is developing so rapidly and absorbing.

»  NAN AHSER: That was Brooke and Lucy is her daughter, youngest of the four kids and Brooke was an experienced mom and I wanted to point it out and I was very appreciative she was willing to share her home birth sorry on that. So your next challenge moving on is replacing older machines. Some machines are ten years old, one is eight, and the life span is five to seven, and the birthrate for home is the same as hospital, or near, which is nice it's not something different. And doing trainings with the newborn, um, new midwives, is the ongoing training gets more and more difficult as some have been trained and some have not.  Mostly troubleshooting, getting the background, taking the online course so they have all the background with them and that seems to facilitate that.

And my last one is the lower cost of the Q screeners, which is the electrodes are cheaper, but the ear tips are ungodly expensive, so I need to find another supplier for that, and that's not something I thought about when I bought the machine, and so I have to point that pout you.  And the midwives, their systems are for the State of Michigan is complicated and they have to mail it in. Okay. I have a couple minutes, any questions anybody has? Two and a half minutes. Do you want come talk on the microphone so the captioner can get you?

»  Audience member: Which way do you want me to stand? Okay. Hi. So I'm from Florida and we just start reaching out to midwives, and birthing centers and the coordinator, so now I'm taking on birthing centers, and I'm meeting them and it's been an amazing experience, with the midwives, in Florida prospect been to 16 so far. My big question, why on the 86% of babies getting screened? Not the 99 I want that.

»  Nan: Yeah, I would like that to. The parents sometimes don't do bloodshots, I had two one here and 0 hearing screening. So it really depends on the population and who they are dealing with, and I know parent choice is a big part of that. But good question. Anymore?

Okay. Well, um, my e—mail is up there if you have a question later that you think about, feel free to e—mail me and I am more than happy to help and answer questions. Thank you so much.

[Applause].

[Applause].

[Applause].

\*\*\*\*\*\*\*\*\*\*\*\*\* 10:10\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

»  Test, test.

»  Okay?

»  Good morning. Happy last day of EHDI, unless you're here tomorrow for more instructional sessions and field trips I hope you have had an amazing couple days, I’m Ashley, coordinator and outreach programs for the Colorado School for the Deaf and Blind and Dawn will explain more be we have a contract to talk with done.

»  Hi, I'm Leann Glen and coordinator for the state database for Colorado, housed at the Colorado Department of Health and environment and we're really happy to be work, Dawn to fill the gap and she's going to talk about everything we're doing to fill gap and progress we have mind.

»  Dawn, and have worked with Northstar Audiologist, and the state organizations and it's really fun to see some of your faces. Just old classmates and things like that are really exciting. So I'm here today to talk to you about a passion —— thank you —— a passion of mine.

And that's newborn hearing screening. I've been involved for twenty—plus years. I coordinated the legislation for Kansas for newborn screening and then moved to Colorado and have been here for three—years. So I’m going to tell you about that wonderful hearing screening and the journey of midwife and home birth. So this is my daughter. He name is Crystal, and this is my granddaughter, her name is Bella and Bella was born at home, —— sorry —— with a midwife in June of 2020. So we're kind of right in the middle of COVID.

And one of the things that happened was at our 24—hour home visit, I asked the midwife, where is my granddaughter going to get her newborn hearing screening done?

She said, I don't know, go to a clinic or a hospital. So I don't know how many of you have had homebirths, but home birth families don't really want to go to a clinic or hospital, so my daughter said I'm not going and not doing it. My pediatric audiology heart fell on the floor.

I was like you are too going to do it. I grabbed my hearing screening equipment and I said, do you mind if I do it? The midwife said go ahead, plug the baby in, do the screening and it was so fast the midwife was impressed. So I lovingly give the midwife credit for starting this program. Because she said wow, that was really fast, do you think you can do it for the rest of our families?

And in that minute, I made a decision that this was going to be an awesome program.

So going into this, I knew some things, I knew about legislation and screening, and I knew Colorado was ahead of the game because in 1997, they had law written and in place and in Kansas, I don't believe the law was written until 1999, and didn't go into effect into 2000.

Our low in Colorado was revisited in 2018 and said effective 2020, would be response for doing screening, or telling the families where to get screening. So when I told my midwife about this, she said just do it in the first three—months and my heart sank and said, you mean one month, right? And she said you don't have to do it if you don't want to.

[Laughter]

Midwife leaves and I looked at my daughter and said we got a lot of work to do, and we were off and run. Something else we knew, the EHDI equipment had a piece about birth and, when you look at Colorado having 60,000 births, it's not high on the priority. And if you look back at March 2020 anybody, think happening some

March 13, of 2020? COVID. And it was not a priority, so we also know about a study done in for practicing, and this was written by Martha Modder and Mr. White and the information provided plays out in real life, 91% of respondents said it's n not my responsibility, what I saw in the field was midwives, saying federal mandate, federal problem, okay? We looked at lack of research and knowledge and my personal experience was get it done by three months, that's not our EHDI standard, we also preach 1—3—6. So that was all at play and playing out, so I really felt I had the research to help families.

What I didn't know going into it was understanding the home birth culture, the community things like sovereign birth, unassisted birth, birthing centers. It was all new to me. I have a little story about sovereign birth, that means the baby is born at home, undocumented and don't have a birth certificate, okay? As a newborn hearing screening person, I need to go into that family's home and respect that.

Okay? That's their choice. That's what they want for their family.  It's not illegal. It's just different.

It's a little mind blowing if you're not there. If you don't understand what's happening. Or don't know how to respect that community.

So now, how does my newborn hearing results get to the state database when there's no date of birth certificate for the baby? I just have this random piece of newborn hearing screening information, the families wanted that information, they want through that process. When the baby is born without a date of birth certificate, there's an affidavit, a document that proves your born at the time and someplace.

So understanding the level and culture, and the different types home birth and the other understanding we need to have, was that the midwives have knowledge of families and know what works and didn't work. So we also need to know the certified midwife is direct—entry, and strengthened not state, but a certified nurse mind wife is somebody who is gone to school to be a nurse, and also gone to school to be a midwife and bring that together. And there are midwives that work in hospitals too.

So one of the things —— whoops, I didn't mean to move from a microphone —— one of the things we did going into this project was go to midwives, and ask them: What's going to work in your community? What's going to work with your home birth families?

So I jumped into this wondering, why am I going to go?

This is a actual place I did a newborn hearing screening. It's a little, tiny cottage in the woods.

I also went in with an open mind and open heart. So when I did the newborn hearing screenings.

[Laughter]

Sorry this kind of makes me chuckle, when I did the newborn hearing screening in barn with cows and pigs, I thought, this is a new definition of a manger.

[Laughter]

I thought oh, my good knows, the midwives, said they don't want to go to clinics and hospitals, and they want us to respect that they did it for a reason.

So we went into the home birth project goals, we wanted to increase the home birth, our very own Hands & Voices' Sarah Kennedy reported up to 30% of home families were getting screenings and have data to support that.

And the hearing screening coordinator, as responsible to the Department of Health, is to find these missing babies. Well, in Colorado, everybody baby born at home is considered first, so approximately a thousand births every year were missed for newborn home screening.

So we had three interventions. In 2020 we knew we were not doing anything for these babies at all, mostly because of COVID, and in 2021, I started Northstar Audiology, because of that midwife that said I don't know you can go to the clinic.

And in 2022, me and Sarah went to the meeting of midwives, and we were able to talk to them about what they thought would work. And in 2023, we implemented what the midwives, told us would work.

I believe the graph will show you, once we listened to the sweet spot of what the midwives, what they said would work we really improved the access to the families. This is the 2022 slide October ‘22 to October 2023 so Leann and I met with the midwives, September 30th.

They told us what would work and implemented it in October, so we went back to the midwives, and said how much and so about 30% were getting screening, so you see low of 84% to the high of 100%.

So in the timeframe of October 20 22 and October 2023 we had 265 babies that were referred. Total screened of 243. We had 8 families decline interest we stalked to the families about why, many don't want to be in the database, and that's their religion or belief system and that is to be respected.

We did have 14 families that did not respond. There is 14 families that didn't respond. When we say didn't respond, we texted them three times, called 3 to 6 times and called them 3 to 6 times and felt we were bothering them and needed to stop.

This is the whole picture, 92% success rate in hearing screening, 3% declined and 5% did not respond.

Over time, you can see through the various years, 2020 when we weren't doing thing, 881 and by the end of 2023 only missed 526. Thank you.

[Applause].

Whoever did that.

»  Um, we did want to kind of look at the data to see if there trends so July to December of 2020, we weren't doing anything, July to December of 2021 we were offering to go to homes and do newborn hearing screening, as in 2021, we offered a power hours session with midwives. You can see not much difference.  The next 6—month chunk we actually we want out and sat with the midwives, and asked them what would work? We asked them, what does your home environment look like?

What does your, um, families look like? What are their belief systems? What are some things we can do to help them get the newborn screening, but not feel threatened about being in a system they don't want to be in?

So we spent time getting to know them and the community.

And the next 6—month period, July to December 2023, we implemented what they said.

So we're going to head back to those goals: Can we increase the amount of homebirth families getting the, the newborn hearing screening? The answer is yes, they also want the screening but in a way respectful to their belief system.

Can we improve the missed screening at the Department of Health? Our goal was 50%. We only hit 40%. But dang, we feel really good about that 40%.

So there are some challenges. I just wanted to be really honest. Our pilot project was based on volunteer midwives, who said they would refer a hundred percent of their home babies, I work with over twenty midwives, from Denver to Pueblo, some of them are not on board. They need data entry, they have the equipment but need somebody to do data entry. Some of them don't want to refer any of the families, they kind of want the teams to do it themselves and if they get around to it, they get around to it.

Some of them want equipment in their own hands and we're not able to provide equipment. And some of them just want somebody to just handle it for them. The midwives, wall that their midwifery coordinator, and I do go up to the mountains and up to Evergreen, and as far west —— sorry direction-

[Laughter]

As far east as the Kansas border.

And funding continues to be a issue, but that's with everything. I just want to say thank you for listening and if you have questions? And this is not research, this is just antidotal information.

»  We have time for questions.

»  Audience Member: First off, your project sounds amazing. So in our state, the midwives, are doing the screening. Which is awesome. But we are a two—stage screening state so the issues we have is the rescreens not always occurring. And we have a really hard time finding a primary care provider from the midwives, even so we can refer the baby to the audiology. Do you have something similar going on, or is there any way you have found to get that information from the families or the midwives?

»  So within our project we had a hundred percent of the babies referred to me and my agency. We had direct contact with the family.

So if a baby wasn't screened, or missed a screening, we could talk to that family directly.

So that's kind of one of the things being that coordinator person, I was able to reach out to the families as well as the midwives. We have a between—stage as well. In midwifery, it looks different than in hospitals. So our first the newborn hearing screening happens within a week and our second the newborn hearing screening happens in two—weeks. Everything usually wrapped up by one year. We have one midwife that does screenings, and she does one week and two—weeks and then referred to me for diagnostics and I ask the family what insurance do you have, where do you want to go? If they don't want to go to a hospital or clinic, I will go to them and do the diagnostic in the barn.

[Laughter]

»  So are you, buy this equipment on your own? Your own money? Way to go. That's incredible. And are you billing family's insurances for, like, screening? What does that look like?

»  Okay. So this is really a cool, um, question. So thank you. So I did buy my own equipment. I'm a pediatric audiologist. I did have a piece of equipment that I started with. It was Macor arrow scan, from 2000. I've just kept it calibrated and that's what I started with. If I go to the families, they pay me, Medicare will pay for home-based services but most insurances don't. So I have a scale. I tell families its contribution based and you can pay whatever it takes. Whatever they feel comfortable paying, if I come to you, it's about the screening, and most families pay and are very generous.

I did have a transit family coming for a family that birthed on a couch and the midwife contacted me and said they're only here for two days, can you come? And I said yes, did the screening and the family left the next day, and it was all taken care of. So...

»  Yes. I just had a question kind of about the data. So was it a thousand, like, all of Colorado has a thousand?

»  It's approximately a thousand babies that are born at home.

» Those are the homebirths?

»  Okay. So the 891 that was the missed?

»  In 2020?

»  Yeah.

»  That was an actual count from our statistical person at —— his name is Steve —— he's at the Department of Health and Environment, I'm looking at Leann because she can fill in the blanks better about where that data came from. I took his number of missed babies in 2020, and that's what I was looking at.

»  I was wondering if those are the missed babies of home birth or all of Colorado?

»  Of home births, correct, Leann?

»  Yes, that's correct.

»  We have time for one more quick one.

» All right; I was just curious if you have done any work or network with Doulas and if that's maybe another route to get into these families?

»  It is another route to get into the families, I have talked to them. There seems to be a rub between midwives, and Doulas, about who, so either the midwife wants to do it, or the Doula to do it, but they want Doulas moved to another position. However, I think it's a wonderful idea.

» I think we're out of time, but luckily for you, there's a twenty—minute break next, so you can come up and chat more if you would. Thank you all. Enjoy the rest of your conference.

[Applause].

[Applause].