

NCHAM-Lost To followup Webinar
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>> Hi Chuck. Just going to do another quick audio check and see how things are going. And Linda and Stacy, if you would like to do an audio check also.

>> STACY JORDAN: Good afternoon everyone. I'm an audiologist with the department Early Hearing Detection and Intervention Program.

>> LINDA HAZARD: Good afternoon. I'm an audiologist with the Vermont Early Hearing Detection and Intervention Program.

>> Chuck: Great. Thank you very much. Several of you, it looks like you're very a little bit of difficulty with the audio part of it. Oftentimes that's on your end. You might want to try adjusting the volume on your speakers or headset. And if that doesn't clarify it, go ahead and log off and come back on. Sometimes that second try gives it a better connection. It looks like most people are hearing us pretty good on that.

>> Jeff: We'll get started in about three minutes. People are signing on now. So we'll give about another three minutes and give you time to get something quick to drink and get ready for the webinar with Stacy and Linda.

>> Audio recording for this meeting has begun.
(Music)

>> Jeff: Hello everyone. Welcome to today's webinar. (Music is still playing)

With an overall goal of reducing the number of babies that are lost to followup. I'm Jeff with Utah State University. This webinar is being recorded and will probably be available within the next week on Infanthearing.org. Also, during the end of today's webinar we'll open up a text box where you may write your questions for the presenter to answer.

Stacy Jordan is the project coordinator for the Vermont Early Hearing Detection and Intervention Program. And also the state representative on the Addology Advisory Council for the State Speech Language Hearing program. Her projects have been both on the state and national level. She established and coordinated the newborn infant hearing screening program at Vermont's children hospital. She coordinate the Hearing Outreach Program or HOP, and also directed Vermont's EHDI's program for several years.

Dr. Linda hazard has a degree in social policies. She used to work for Adviced Bionics, Cochlear Americas. And once again, I would like to welcome all of you to the NCHAM webinar. And now I'll turn it over to you Linda.

>> LINDA HAZARD: Thank you, Jeff. And can you bring up the first question?

>> JEFF: I will do that in just a moment here. There we go.

>> LINDA HAZARD: If everyone could respond to our first question, I would really appreciate that.

Okay, so it looks like we have about 45% of the callers are working in EHDI programs. We have a small percentage who are in primary care or pediatric offices. We have a small percentage of audiologists and then a percentage of about one-third are other. So thank you so much for providing this information to us. And I'm going to move onto our first slide, which talks about lost to followup. And for many of you on the call today, you're familiar with the term lost to followup if you're involved in an EHDI program. But I'm going to go through that for those of you who are not.

Lost to followup is a CDC statistic. It's gathered on annual birth data for hearing screening. And HRSA and NCHAM have a goal of reducing lost to followup by 5% a year, and the goal is to have it under 20%. With lost-to-followup, it's a small subset of births. It's the denominator of infants who did not pass a final hearing screening. And the numerator is the number of families who we have either been unable to contact, or those family who is have not responded to calls, letters, et cetera.

So I'm going to have Jeff, if you don't mind, if you could put up the second question. Because we want to learn a little bit more about your experience with hearing screenings. And then I'm going to turn the next slide and discussion over to Stacy Jordan. Thank you.

>> STACY JORDAN: Thank you, Linda. I'll just give another moment here for people to respond.

Okay. so it looks like there are a third of you who are providing hearing screenings already, and then there's quite a few of you that are interested in helping other offices, practices, and programs establish a hearing-screening program, which is exciting to see. And hopefully you'll be able to take a few things away from our pilot project that we're going to share with you today.

So many of you state that had you're from EHDI program in one capacity or another. For those of you who are not, as Linda mentioned, we just wanted to share a few things. Through our EHDI programs nationally we work very hard with our 1-3-6 goals. That is to screen infants by one month of age, have their diagnosis by three months of age, and if they have any degree or type of hearing loss at six months of age. We work really, really hard to reduce lost-to-followup all the way along the 1-3-6. But we can't do this alone. I'm going to share who some of our partners are.

This is our village here in Vermont. And as you can see, the family is always in the center of our entire efforts. And these are all of our various partners that we work with and depend onto help have a successful EHDI program and to also help reduce our lost-to-followup. Our hospitals, providers, audiologists, early head start. And we also have a robust relationship with our home birth midwives in Vermont, which has been a wonderful, wonderful partnership to reduce our lost-to-followup in Vermont. We've been working with our partners in many ways to help reduce our lost-to-followup. I want to share a little bit more about the work that I do in our program, and some of the strategies that we've been working onto reduce lost-to-followup over the years.

My role in our EHDI program is I do all of the care management for babies who either don't receive a hearing screening or do not pass their hearing screening, and try to ensure that they move through the 1-3-6 program working with that whole village: The families, providers, audiologists.

And a lot of our efforts have revolved around with reducing lost-to-followup by pulling quality assurance from our registry, ensuring if baby has been born and we don't have a hearing screening on them, or if we do have a screening but followup hasn't occurred. I make lots and lots of phone calls all day, every day, to families, providers, hospitals, audiologists, trying to make sure that these families and these babies move through our continuum.

We also send letters. Sometimes we are not successful in reaching families by phone. Or we are calling telephone numbers where there is just an automated message, so we don't know if we're really reaching who we think we are. So we do send out letters, which we also copy to the primary care provider. And then as I mentioned I make lots of phone calls all day, every day. So more phone calls are made.

I have helped cover some staffing gaps with audiologists at the hospital when there aren't technicians there to provide hearing screenings. I've done that, as well. And I've also attended some primary care appointments. As you can see, we are pretty tireless here in Vermont to try to do any type initiative that we can to find these babies, help these families with following through with the screening process.

So even with all of these efforts and all of our partnerships, sometimes finding a family is as easy as finding a needle in a haystack. Families move, they change addresses, they change phone numbers, they change primary care providers. We work very, very hard. We do everything we can. And many days half of the callers can empathize. As EHDI staff. Whoops. I'm sorry. I'm having issue with the slide. Like this. (Laughing) I think some people can empathize with how hard we work. We work really, really hard and we are still seeing that we have families and babies that are falling through the cracks.

So our EHDI team got together and started brainstorming to try to figure out maybe if there was another partner or there's a gap that we could fill to try to continue to work on our lost-to-followup. So we all started talking about the journey of having a child.

And this led us to come up with working closer with our primary care partners. They're the ones who are there at the birth, at the hospitals, they're the first one to see the families and babies after the birth. Baby has many appointments, many frequent visits in the first days, weeks, months of life. And then they're also as stated a primary care provider. There's that ongoing early childhood care that is also happening. So there are many, many, many appointments that happen. Over the years of making these endless phone calls to primary care providers, I often heard comments like I wish we could just do this in the office. Can you just come here? It's hard enough to get family to come to our appointments, nevertheless get them to come to another appointment. Wouldn't it be nice for families to have one less appointment to attend or to schedule when they have a brand new baby that's become a part of their family?

We really wanted to move forward with this process after our brain-storming session, but we realized we had a lot of next steps before we could implement this idea. First was writing this pilot project into our HRSA grant. We also had to talk about what kind of equipment is going to be appropriate to bring into our primary care settings. And then we have to choose sites. How are we going to choose who we're going to work with? So I'm going to pass this back to Linda who is going to talk about how we approach new ideas and changes in our EHDI program. Linda?

>> LINDA HAZARD: Thank you Stacy. Whoops. And I'm having trouble for a moment. Sorry. With the slide. Jeff, it's not advancing. Oops. There we go. Thank you!

As a program, we began to look at the model for improvement both through the NICU collaborative, which was held. As well as our own Department of Health in Vermont was looking at using the same model of improvement. So really what we're looking at, those

of you involved in EHDI programs, you've become very familiar over the last few years about the model for improvement with small tests of change. So we implemented "plan, study, do, act" cycles. And we use this in every aspect of the program when we're looking at quality improvement. We start small. We test, we test again. And then we may adapt. We may adopt. And spread. And there have been those times where we've abandoned the change that we were working on, because we realized it was not an efficient way to approach a change. Or it was not, it was not, we were not seeing the results that we were looking for.

So I will move onto the next slide to discuss the project aim. So with the primary care pilot project, in the state we had set an overall goal by April of 2014 to decrease our lost-to-followup by at least 10% per year through developing 10 primary care pilot sites, providing OAE hearing screening. I will say in addition to this pilot project, as Stacy mentioned, we were also working with the midwives very closely to reduce the lost-to-followup for our out-of-hospital population. With this program we hoped it would reduce our lost-to-followup. We used small tests of change. We used the model of improvement. And we started with one primary care practice in Vermont. And then we moved to a second primary care practice, or excuse me, we moved on after we had worked with this one primary care. Found all the challenges and all the opportunities. And moved on to the second primary care provider offices to work with. And we chose two additional ones. We went onto do another two additional primary care pilot sites. And these were all done in PDS arc cycles that took us approximately a year and a half to begin these projects. And we currently now have ten active sites that are partnering with Vermont EHDI across the state.

So you might want to ask, okay, how did you choose these primary care pilot sites? And let me give you the map of Vermont that shows where the ten sites are currently located. And Stacy, I'm going to turn it over to her. And she is now going to talk a little bit about how we initiated our PCP pilot project and how we began to choose the sites across the state.

>> STACY JORDAN: Thank you Linda. So our first question as Linda stated is who are we going to approach? So again, we went back to our registry where we can pull many different types of reports and data to start looking at various different reports to help us decide who to pursue. So when we started pulling these reports, we wanted to look at well, where, if we pull all of our lost-to-followup babies, are they concentrated in specific practices, specific counties. Sometimes is it just seeming to be with a single provider? We also wanted to piggyback our high-risk patients, birth to five. So we pulled our reports on any children in a practice, once we started to narrow down the practices we may want to pursue, to see if they also had a high percentage of our high-risk patients that we would want to maybe in the future, maybe not right away, but to provide annual hearing screenings for our high-risk patients, birth to five years of age. For those of you on the EHDI program, you're familiar that we have a list of high-risk factors collected at birth. These high-risk factors turn into a flag in our system that even with babies that pass in both ears, this flag stays on their record that there's a factor for late-onset or

progressive hearing loss, and there are some additional hearing monitoring and recommendations that our program has put into recommendation.

And obviously location. When we started with our first one, we were just looking at where is the majority of our lost-to-followup. But as we started to add more and more pilots, we wanted to make sure they were geographically spread out across the state so we could make sure we were getting all corners of the state with the opportunity for this pilot.

The next big question is whether or not these practices are even interested. We did have some practices that we thought "Oh, this is going to be the perfect one." They have a really high lost-to-followup rate or a lot of high-risk babies. When we approached them they were either not interested or felt they didn't have the capacity to take on one more thing at this time.

Once we did start to find interested practices, we as a program had to stop and think how do we want this partnership to work? We want to really make sure we have our expectations of what we were going to do as an EHDI program to support them and what we were going to expect in return in this partnership before we moved forward with really setting this up formally.

So we wrote a memorandum of agreement that we did have our practices sign for the first year. I'm going to tell you a little bit more about it. It was for just the first initial year. And what we in general is asked the practice that they would screen all newborns that we sent a flag for referral. So newborns who either didn't get a screening before they left the hospital or they didn't pass their initial screening in one or both ears. And then they asked that they report all of those results back to our program. This was either in written form, fax form, or we have also over the year to directly data enter right into our registry.

In return, our program said that we would provide the OAE equip. We would actually purchase and bring in the equipment. We would come in and do initial training with the entire staff. We would give them supplies for a year. All of the ear tips, and the initial calibration at the end of that first year. We would help provide care coordination and management, which is my role. Any type of support that they need, and I'm already there along the way with the newborns to help them determine who needs to be screened, how many screenings to do, and when it's time to move onto the audiologist.

Ongoing technical support and training. So this comes into equipment breakdowns, maybe a staff member that seems to be having a lot of high referrals or is unsuccessful in offering that additional training. And in that first year I, or one of our staff, we did four in-person staff visits in that first year. That was our part of the memorandum of agreement.

In my experience, I would say the most important initial first step is once you get a

practice that says yeah we want to do this, we want to take on hearing screenings in our practice, is to establish one single primary point of contact. That is going to be your go-to person no matter what. If there's too many points of contact, it gets very, very hard. And we have a small staff. And a lot of it falls on myself and it's a lot easier when I get to talk with one point of contact and I don't have to learn and understand five different people's roles at a practice. So I have found that that's a really, really important thing to do.

So once we decided on our first pilot and any of our pilots that we added on over the years, the first step was just to have a phone meeting. I didn't even have an in-person meeting until we had this first phone meeting. And in the phone meeting, we discussed the memorandum of agreement, just as I had shared with all of you. The various details of what they can expect from us, and what we're expecting from them, and really making sure that's really clear and out on the table. We talked a little bit about who in their practice is going to provide the hearing screenings. So that varies practice to practice. We have some practices that they have medical assistance, they have the nursing staff to it. They just have one designated staffer that's been trained to do it. And we even have some practices where there's a couple pediatricians who have latched onto OAE screenings, and they provide those screenings themselves to patients. There's not a lot of those. I would like more. But we definitely have a few.

I also discussed with them whether they want provider participation. If the nurses are going to do it, what is the provider part? Do they want me to come in and do an overview presentation to the providers to explain what the hearing screening is? How it's done, and what the process is so that they can feel educated and prepared to support the rest of the staff who is actually doing the hearing screenings?

And then once we've had this discussion, if they still wanted to move forward, we would then at the end of the call schedule a date for the initial face-to-face training after deciding who is going to be there, how much time we have, and the date and location of that.

I will tell you in working with many other people on this call, we would love to have a half a day, whole day, to train people and be with them. But in primary care settings, that's not really a very realistic expectation. So many times I had an hour, and it was over lunch and that was the initial step. So there were times where those four in-person site visits were not enough if the staff was really feeling they needed more time with me. Or I would do those one-hour in-person trainings and stay. And they would schedule a bunch of kiddos to come in and I could be in the room to help them with their initial hands-on screenings with children of various ages, including newborns.

As I mentioned the next step after the initial phone call and meeting with uh to schedule the initial training. We decided whether or not the providers were going to be there and whether they were going to train or not. Who the staff were who were going to provide the training. We would bring the equipment and do hands on. We would do general

overview of what OAE hearing screening is. Making sure they understand our 1-3-6 goals and what their role is, and there are sometimes when I had to do this in two stages and sometimes both providers and staff would all come at one time.

The last pieces are ongoing support and technical assistance. And this still continues on as we speak. So there is always ongoing equipment troubleshooting questions. I have had practices who do great with their equipment for years and then all of a sudden something happens and they don't remember all of those great little tricks and checks that we talked about two or three years ago when we first started.

I get a lot of phone calls and e-mails about tricky cases. That's working with various ages, and also newborns, how often to screen, and when to screen, and different tricks of the trade to work with babies and children.

New staff is a huge part of our ongoing support. And it's just staffing transitions. You had your gold star. We just lost probably my favorite screening nurse ever to a practice. I'm very sad that he left. He was our total hearing champion. And when you have staff that are there for so long that really embrace with hearing screening, it's hard when that transition happens. Because you have to go back in and support that practice and maintaining the wonderful service that they're providing to their families.

I still do some site visits. If it's needed. They're much more fewer and far between. And this is again if there is a new surge of new patients. Excuse me, new staff. If there's some additional interest from providers. I've had some staff ask me to come in when providers have challenged continuing the hearing screenings because of the time it's taking for the nurses to participate. But most of my check-ins are by phone, e-mail, and then I also do quarterly newsletters to the practices, as well as, our practices have been established for over a year now. We also send them quarterly lists of all of their high-risk kiddos in their practice, birth to five. To say if you have the capacity, if you would please provide hearing screenings in the months of January, February, and March, for all the kids on this list.

We've done a lot of work as Linda shared. We have our ten sites established around the state of Vermont. I'm also happy to say there's a few additional pediatricians in their offices who have bought OAE equipment on their own. And we've done some outreach to support them, as well, even though it wasn't part of our pilot.

As you can imagine in working with any type of partnership or collaboration, there's challenges and there's also many, many successes. I've already alluded to many of these, but I'm just going to review them again.

A lot of the challenges are just finding the interests. Finding a practice that says "Yeah, I really do want to take this on" versus "Oh we can't do one more thing." And that they have the capacity to actually do a hearing screening program well. Many of you on the phone who are either involved in EHDI programs or hearing screenings at different

levels, hearing screening programs are extremely valuable. But if there is no follow-through and referrals and next steps, that screening program is not a strong screening program and we're not really moving forward in my opinion.

There are a lot of different workflows. If you've been to one primary care office, you've been to one. They all operate very differently based on their size and who they serve and the number of doctors and the layout of the office, the physical layout changes things. I can't just do a one-size-fits-all training on here. Here, this is easy. Just implement it into your practice. It is very unique to each practice.

I do encourage the practices, I have a list of my single points of contact to talk to each other. I am not working in a primary care office. I do not know what it's like to balance hearing, vision, immunizations, check-in, check out, all of that. A lot of times I'll connect practices with each other so they can help each other with brainstorming ways to implement or get over challenges that are happening with their hearing screening programs.

As I mentioned in-depth, staff transitions are always a challenge. We're having some issues with lack of reimbursement, or inconsistent reimbursement with the OAE screening code. So that is something that is continuing to be a challenge. And that is hard with buy-in. So if they are not getting reimbursed for the service that they are providing, it's hard for them to be able to justify continuing to provide the screening and their staffing time. Though we are on the phone and in newsletters often encouraging them of all the reasons why it is so beneficial even if they're not being reimbursed.

We have a lot of holes in our audiology program across the state. We may have a great program in a community, but it's still a great distance to the audiologist when it comes to that point.

The last challenge I want to mention is documentation. I know this is probably a challenge in many different levels of EHDI program and hearing screening programs. But just helping the primary cares understand when they need to screen, how often they should screen, reporting the results on time. Reporting the results accurately. Who to share the results to. Making sure that they're following a timely protocol. And then followup. That once they screen and refer out, that really working with them to make sure that they close the loop on those kiddos and making sure that they actually get to the audiologist and find out what the hearing status is.

So with our challenges, we've had a lot of success, which I think is probably obvious since we didn't abandon this after one pilot site. We're finding this to be a wonderful partnership, which I am still so thankful for with the ten sites and the additional pediatric offices that are doing this.

We have successfully established ten sites statewide. We've had some other practices come to us with some interest. At this point we've said we're here for training and

support, but we don't have the pilot design to be able to make the initial investment for equipment for them anymore.

So hopefully a few more will still want to come on. We do have a few practices that have expanded out to that high-risk population, which is amazing. So my dream as an audiologist is that one day we will have early periodic screening birth to five for every child. Regardless of their risk factors. So to have these practices opening up their capacity to start screening our babies that are high risk at their first, second, third, and fourth wellchild check is just wonderful.

This partnership, even some of them that did not finish. We had a few that started that ended up feeling like they couldn't do it. We still felt like it was successful, because they have an increased knowledge of what our EHDI program is. What our goals are, why we're calling, and why we're following up so closely with these babies and families.

We see there's been decreased number of appointments at audiology offices. Going back to the hospital throughout patient screens. It's a success because it's one less appointment for families if they can get it done at the medical home.

We do look at our numbers and these practices now and they are not the ones that are bubbling to the surface with our lost-to-followup. So we've seen a decrease in the number of children that have been lost to followup in these practices and over all in our program. And I'm just going to ask Linda if she would share a little bit about our lost-to-followup numbers during this pilot process.

>> LINDA HAZARD: Before I move into the lost-to-followup numbers, I just wanted to reiterate something that Stacy said, which is about buy-in. And one of, sort of a cute conversation that I ended up having with one of our pediatric providers.

Stacy mentioned that we often will fill in either in the nursery or for some of the audiologists when they're not available. In our largest tertiary care hospital, which has about half of the births in the entire state, the hospital uses technicians. So we run into times when the technicians are out or they lose a technician. And one of us will go up. I had an experience where I was in the newborn nursery screening. It's a captive audience when the pediatricians are there. I happened to be filling out reports. He sat down next to me and I kind of brainstormed with him about this idea. So what I would say to you is the first challenge to overcome is getting buy-in from the provider offices. Once you get your foot in one door, they talk to each other. And often it's much easier to gather and make the next, to be able to do another PDSA cycle or with a second or a third primary care office.

So I'm going to talk for a few minutes about our lost-to-followup. I started in the EHDI program in 2009. It was when we initiated halfway through our fully-integrated database. Our data is integrated with electronic birth records, electronic death records, immunizations, newborn screening, and newborn hearing screening, as well as led. It's

very, very helpful because we can gather information on many different areas. We almost always have an accurate PCP because of it. There's a lot of cross checking, so we don't have duplicate information.

That has really I would say catapulted us to be able to become a very data-driven program. I happen to love quantitative data and I love being in the data weeds as you might say. So one aspect that I have been working with NCHAM on is I have a coach or a mentor from NCHAM who is working with us on looking at our data in realtime. So over the last couple of months, we pulled all of our 2014 data, cleaned it, have been really looking at it closely. And my coach or mentor from NCHAM has been working with me on charting our progress. So currently what I'm doing is charting all of our 2013 data through October right now.

I want to share our lost-to-followup rate for Vermont starting in 2009, which was at 54% at that time. You can see from the runchart, in 2010 we brought it down to a little over 30%. We bumped back up again to 39%. And then slowly have been decreasing to our preliminary data in 2014. We're at under 2% lost-to-followup, which was really exciting for our team, especially with the amount of time and effort that we have been putting into PDSA cycles and moving through how we could improve our data. One of the things we're most proud of is that our lost-to-followup, not one single infant came from our primary care pilot sites. So we have really worked very closely with them and we are now starting to see the rewards.

I wanted also to discuss some strategies we have used. We did use PDSA cycles in choosing them and working and mentoring. But we didn't stop there. And Stacy alluded to some of the other PDSA cycles that we worked through, including we introduced and implemented a web-based reporting system in 2012. Towards the end of 2012.

The reason, so when we became an integrated database, because of the immunization database, our providers, PCP providers and audiologists were able to have a read-only access to our database. So if an audiologist was seeing a child, they could go in, find out whether or not that child had had an initial screening, what the results were. We took it a step forward so that we could have web-based reporting. Various pilot projects with primary care, midwives, and early head start programs, we realized the fax were getting confusing. Something could fall through the cracks.

We began a process through our last CDC grant to do design and implement web-based reporting. We did it slowly using PDC cycles. We wanted to make sure at each stage as we needed to adapt, to make it easier for providers to use. That's now been fully implemented for close to two years now.

We also as Stacy mentioned introduced and implemented quarterly newsletters. One of the reasons for that was because we wanted to be able to give them some tips and hints. And one thing we came across as a two-step, most of our hospitals do a

two-stage screening. So OAE is first. And AABR screening is second unless the baby is in the NICU, and then it is also recommended in Vermont that a child have an AABR screening.

So we ran into a couple places where our primary care offices were so excited. They knew a baby had lost a screening, so they screened them with OAE, and they should have screened them with AABR. It gave us an opportunity to say these are some tips and hints. These are the babies who should have the screening. We used a survey to see how they felt about the newsletters. It's something they said they liked and found beneficial. It's something that we're contemplating sending out to all of our primary care providers, just as an FYI for them.

We also introduced and implemented a general satisfaction survey, because we wanted to know how the primary care provider offices felt about this collaboration with the Vermont EHDI program. We did something very similar with the midwife project, as well, and with early Head Start.

So what are the lessons learned, and what are our next steps? We really learned the importance of collaboration with our pilot sites. We realized how value they felt, and how much value we received back from them as far as being part of this pilot project. We truly feel like we're a team. We're working together. The pilot sites are very responsive to us, we're responsive to them. And whenever we can, we'll give them a little extra here and there, whether it be supplies or picking up a calibration, or picking up a new probe, whenever we can. Just to continue to keep that partnership going. And I think that the collaboration has been key for both us and for both the primary cares.

We realize that the PCP pilot sites as well as the Early Head Start pilots have really had a significant help in increasing our lost-to-followup numbers.

What are some of our next steps? Stacy mentioned we do have the reimbursement challenges for OAE screening. We're still working on that. And that's a national issue, not just a Vermont issue. Of

My goal and my thought is we've implemented hospital report cards that we've been doing for many years now. We moved onto midwife report cards for our out-of-hospital births. And I would like for us to send out primary care provider report cards, so we actually look at their number of babies who were either discharged out of the hospital without a screening or needed a rescreening and then captured those babies that were followed by the primary care office.

Additionally we have implemented report cards with audiologists, as well as diagnosis by three months of age.

And lastly, I would also say as Stacy mentioned, we do want to start looking more

closely at high-risk monitoring of the babies between six months and five years of age. For those babies that may develop progressive hearing loss related to the high-risk factors.

>> Darlene. This is Diane. Will you give me a call at --

>> LINDA HAZARD: I'm getting feedback.

>> Jeff: I'm here. I'm having trouble with my phone. We have a crossed line. Hopefully it won't happen again.

>> LINDA HAZARD: Okay. My last slide is reducing lost-to-followup, which has become our motto, which is never, never, never give up. We will go back and look at babies even months or a year later to see if we can reach out yet again. Whether it be with the PCPs, the midwives, or the early head start programs. Thank you very much for your attention, and I would like to open this up to questions.

>> Your call did not go through.

>> Jeff: My apologies for the crossed line. That is our phone company here in Lincoln.

>> I'm sorry. Your call did not go through. Please hang up and try your call again. This is a recording.

>> I'll wait a second.

(Beeping)

>> LINDA HAZARD: Stacy?

>> STACY JORDAN: Yes, Linda. I'm still here.

>> LINDA HAZARD: So you're getting this beeping sound, as well?

>> STACY JORDAN: I think Jeff is hanging up. For those of you who are still with us, I think we may have lost some people who thought they needed to hang up. We are open for questions. We have about 15 minutes if anyone has any questions for Linda or myself.

>> Jeff: I'm still here now. My apologies to everyone for that. We've been having trouble here in Lincoln, Nebraska with our phone. The squirrels have been chewing on the lines. So we are going to go ahead and start taking the questions and I will copy them over.

>> LINDA HAZARD: Thank you, Jeff.

>> Jeff: Are you seeing the questions? Do most of your hospitals screen with OAE there? Over in the notes field?

You can take them however you would like.

>> LINDA HAZARD: The answer to the first question is yes. Most of our hospitals do screen with OAE. It's a two-stage. So if a baby does not pass an OAE screening times two, then that baby will go onto have an ABR screening. We do have I think one hospital that is doing only ABR. All NICU babies, the recommendation is for ABR screening. And as far as I'll take the second one, how many people are on your staff? We have two full-time audiologists. We have a data administrator and a part-time department assistant.

>> STACY JORDAN: Linda, can you just share our birthrate with those who may not know what our birthrate is?

>> LINDA HAZARD: We are known as the smallest birthrate in the U.S. We have approximately 5600 births. That has been decreasing annually for about the last six years. We had over 6,000 and then it's been going down. We are starting now to see a slight increase again in our birthrate. But we are a very, very small birth state. Oftentimes I will say we are like one big pilot project when you look at our state.

And as far as how we handle, I'm just taking the second part of that question. How do we handle the followup with families with the staff we have. It's probably very related to the number of births we have. So Stacy does a lot of the followup work, the majority of the followup work. And then others on the team when Stacy is out or needs additional help, we will all step up and help with whatever we can and need to do.

>> STACY JORDAN: So just for our category, which we all our ASAP, so those are babies who don't get a hearing screening or need a second screening as an outpatient, I am care coordinating about 4-500 babies annually, just to give everyone on the phone an idea of that. And that's only one piece of my job and what we do as a program. But I just wanted to give that little point of reference to everyone.

Linda, do you want to answer the next question about purchasing equipment under HRSA?

>> LINDA HAZARD: Yes. So we originally wrote the first pilot project into our HRSA grant for 2010. And that was a supplemental HRSA grant. And we did receive permission to do that. And we have put in every year since then the purchase of equipment both for our midwives, our early head start program. Currently we have a very small amount of equipment, but most of our sites have been up and going for several years now. And we have, Stacy and I and other audiologists who have trialed and tested numerous OAE screeners have all come back to the ODX, which we find to

be a workhorse. Although it may have some issues in background noise, it seems to have less issues than some of the other equipment that's currently on the market. So we pretty much standby the ODX and that is what we do recommend.

>> STACY JORDAN: I will jump in regards to working with the PCPs. There's a question about protocols. So the national EHDI recommendations, which is what we also follow here in Vermont. That is if baby is screened with an AABR and does not pass, they should be rescreened by AABR, and we can go into more depth of why that is. But that is the standard protocol. With those situations, as Linda mentioned, sometimes our primary care offices are all over this now. Sometimes we'll rescreen a baby before we get the referral from the hospital. But in those case where is a baby does not pass an AABR or they were in the NICU, I do connect with the family and the primary care and let them know that although they have the equipment in the office, that the family needs to go back as an outpatient to the hospital as an AABR, because that is the recommended best practice for that situation whether it's NICU, or if they were screened and didn't pass by AABR. If the baby is screened and passes, we do discuss that it is a valid type of technology and that is great information. But we then really encourage the primary care provider to encourage the family to follow through with the AABR. I'm trying to keep up.

>> LINDA HAZARD: Stacy, I'm going to take the next one I think on reimbursement. Yes. So when we started our first three pilot projects, the OAE screening code was reimbursable. And our primary cares were being reimbursed for that. When the change in codes came two or three years ago now, it is still a reimbursable code, but it has a zero dollar amount. And that's what we're, what's happening right now is we're looking to have that change to, you know, a certain amount rather than zero dollars. That was supposed to happen in October of 2015 and has not yet. But that is something that some of the healthcare committees are looking at and working on nationwide with recommendations, you know, coming in from EHDI, coming in from audiologists, as well.

So for our primary care providers, they went from being reimbursed to not being reimbursed and we were a little worried. But because they had seen the successes and because they had seen so much of how it's the right thing to be doing, they have stood with us, even though they're not being reimbursed. And that's why whenever we can cover supplies or a calibration, we do. Because we want to keep them buying into this process.

>> STACY JORDAN: There's a question about PCPs being open. Linda can July in on this, too. We definitely had a few practices that we pursue that had were not. But I would say the majority of them were very open to at least trying. They wanted to try. We did have one major practice that they really wanted to provide it, and it just, it just wasn't working. So I think overall yes. And we've had some practices come back to us who initially said no and now they feel ready based on a variety of factors in their own

setting. So I think that overall, they were pretty open, especially because we were coming in saying here's the whole package to get you started. Which the initial expense of the equipment is a big deal.

Linda, do you want to talk about lost-to-followup strategies?

>> LINDA HAZARD: Yes. I'll take the next question, which is what other strategies did you use in addition to PCP OAE project to reduce lost-to-followup? So we have a variety of strategies that we've used including the pilot project with the midwives. And we will go into our database on whether we have high track. No, we have a homegrown database that was developed right at the Vermont Department of Health. And so we have, so I'm so sorry. We have 70-mile-an-hour winds where I am right now. They're howling. Apologize if you're hearing that in the background, as well. We have implemented a number of strategies as we've moved forward. One additional thing that we do is we will go back and review any baby without final screening results or final diagnostic results. And we will reach out again by phone, again reach out to the primary care provider. And we, as a part of this pilot project, we then looked at our other babies that were sort of in that lost-to-followup area and identified where the PCPs were. And although they may not have a large number or at this point are not in a place where they are interested in providing those services, they have been very open to us, one of us coming in and providing an OAE screening during a well-baby visit. And that has also additionally helped us reduce the lost-to-followup.

I will say that we constantly go back to our data and I just did this morning and saw a little bit of a blip in April of 2015 where we seem to have a number of babies where we don't have final results on. We're now going back and pulling those babies and looking very closely at PCP, where they may have fallen, where they may have fallen through the cracks to try to identify some new strategies of working with those babies.

Some of them are going to be out-of-hospital births that are called unassisted births. They don't have a midwife. It might be a partner or a spouse that does the delivery. That particular group of babies, families, they're very hands-off on any types of medical intervention. Those particular babies we've not been success informal capturing for a hearing screening.

>> STACY JORDAN: We have not considered ABR equipment in primary care settings for a variety of reasons, like the barriers that they were not able to provide OAE. Time is a huge difference between OAE and ABR. In addition to the cost of the supplies. And the state of the baby needing to be a little bit more ideal than sometimes primary care settings are. So we have not, we have not considered that as part of the project at this point. Our community hospitals are wonderful at bringing babies back in as outpatients. When we need those AABR screenings, we have the community hospitals to provide that service.

A few reasons why babies are able to leave, it is a standing order in Vermont to have a

hearing screening. But it's the family's choice to say I don't want to have the hearing screening done right now. It could be by family choice. We have families who leave against medical advice. They leave very, very early. So it's before the hearing screening would even be offered. As Linda mentioned, there are always the possibilities of staffing gaps. And then we've had some equipment breakdowns, as well.

We do work with the primary care providers and the families through the whole continuum of the 1-3-6 for our babies, but it doesn't end with that. If there is a child that a provider has screened and is concerned about, we are always here to help make recommendations on where to go for audiology, whether the closest site is in Vermont or in our neighboring state. New England is a tight, small area. So we have great relationships and are able to keep a list of who in our neighboring states provide pediatric audiology services.

>> LINDA HAZARD: And I'm going to take another question on high-risk population with direct referral to audiology might not be the best route. It's high-risk monitoring of those babies. So they are followed. They may be followed by audiology depending on the risk. But Vermont has been very proactive in moving from, you know, we make recommendations that the baby be screened at six months or one year. But we have now made the recommendation and are working with the primary care pilot sites so that every baby has an annual screening up until age five through the PCP offices. And that's one of the areas where we want to begin to look at more to see whether or not we're finding hearing loss in this high-risk population.

If we were to refer direct to all needs babies to audiology, it would be an enormous hardship for audiology. There are two major pediatric audiology practices in Vermont. And then a smaller one in the central area. So we really have three major pediatric sites. So we have to be a little bit careful about referrals and overreferring. So this is really a screening process that we're looking at with the high-risk population.

>> STACY JORDAN: The next question is about a buying contract for group purposes. As Jeff will tell you through the ECHO initiative, we always encourage individuals to call equipment companies. We have bought, I don't even know, Linda can tell you, we have 40 + OAE units around the state that we have purchased and we have not found, we've gotten some bulk discount on annual calibrations and that's a whole nother presentation on how we coordinate that statewide with our Early Head Starts, our midwives and our hospitals. But we have not found that the equipment companies have given us a bulk purchase discount for purchasing more than one OAE unit. But it never hurts to keep asking!

I'm just trying to catch up here. We answered that.

>> LINDA HAZARD: So there's a question here. Please clarify the protocol. So our two-stage hospitals will use it if the baby has not passed an OAE screening times two. The baby will then go onto have an ABR screening. If they don't pass that, then they

are referred on to audiology at that point. And if a baby doesn't pass an ABR screening times two then if one has been at the rescreen, then they will be referred on. We do have pediatric sites that will schedule for an ABR screening. And if that baby doesn't pass, will go right into the diagnostic. And that's an area where we're looking to do some more PDSA cycles.

>> STACY JORDAN: I'll just say thank you to the person who shared about Tennessee. We, as mentioned, Linda mentioned we also have ODX. We held with getting ODX training and encouraging units in our Early Head Starts statewide. Thank you for sharing. Tennessee has said that early head start offices have the ODX machines, trainings by the department of Tennessee department of health. And trainings are provided by the Department of Education. That's another unique approach or way to get equipment supplies covered for more early hearing screenings to be done.

We have a lot of levels of approaching families. The question is what is your approach when you do connect with a family, but they reject services, but you realize how it could benefit them. We feel like everything that we do in early hearing, the reason that we're doing this and making these recommendations is because it is a benefit. So we do everything that we can to make sure that the family understands what their recommendations are and why. That we help if we can with any barriers, whether it's a language barrier, a transportation barrier, a financial barrier. We work very closely with the primary care office to make sure there's not a conflict there. That the primary care isn't saying oh, don't worry about it and we're saying it's important. At the newborn level, we do have a way for the families, they can either sign a form or just call us and say I don't want to do this, please don't contact us anymore. We also have a form that they can sign that says they have received all the information and at this time they're not interested in the hearing screening. And then we document that in the child's record in our registry.

>> LINDA HAZARD: And just one more piece of information about Vermont is that we do not have legislation. I just wanted to -- we do have administrative rules, but not legislation for newborn screening and newborn hearing screening. But we have been very successful in our families following through, which has been really helpful.

Oh, no. Go ahead.

>> STACY JORDAN: So there's a question about if we feel because we're a little state if this can be done in larger states. I think it can. I think if anything it just shows that doing this on a smaller scale as Linda has explained with our systems approach with the PDSAs is you have to start small. And then hopefully it will grow from there. I feel that I have some experience with working with the ECHO initiatives with working with Early Head Starts. Some of them are small and some of them are thousands and thousands of kids.

We've had good success in that area too with small states, big states, small cities, big cities, small programs, big programs. I think it is possible. It just takes a lot of planning

and sometimes these small steps to move it forward. It may not go straight to everybody is getting screened. But we started with just one practice and only newborns before we expanded to another practice or even started to ask them to open up to screen other ages.

Do you think that we've covered everything that's in the questions?

>> Jeff: I think there's one more. What was the refer rate for the PCP offices? I think that's the last one.

>> LINDA HAZARD: Can I just ask a clarifying piece on that? Is this question being asked as far as the referral rate of the PCP practices actually doing the screenings themselves?

>> Jeff: I believe so, yes.

>> LINDA HAZARD: Stacy, do you want to take that one?

>> STACY JORDAN: I don't know if I have the, you know, the number of practices. The number of babies. And I wasn't involved in some of the initial starts of the PCPs, Linda, so I'm not sure how we were tracking that.

>> LINDA HAZARD: Yeah. So initially we looked at primary care sites where the referral, the lost-to-followup rate was high. And I think there was an earlier question that Stacy answered in the sense of asking why we have so many babies that are discharged without a screening. And that has to do with the fact that we have technicians at the hospital level of our largest tertiary care hospital. We have been looking at that from a leadership position at the hospital. There are some big barriers and silos. The biggest one is the union for the nurses. It is a challenge for us. That's why there are so many babies being referred. But I will say that the referral rate once that baby is seen in the primary care office and then referred on for audiology is my thought would be below 4% of those babies actually go on for additional testing to audiology.

I should also clarify that Vermont has a very, very small rate of hearing loss. It's been this way since I practiced in Vermont, which I'm going to date myself. Since 1981. In most years we will identify 1-7 infants with hearing loss. Occasionally we'll see 11 infants. But we really have a small incidence of hearing loss in the state.

>> STACY JORDAN: So with those small numbers, we are down to every one baby at a primary care office is a big number for us because our numbers are small. So I can't say that I formally can answer that pediatric office pilot number three had a high refer rate. But we are getting every result that is coming in. So in realtime we're able to address if it seems like there is a nurse who is always referring children on the babies or

if they're struggling. We have an open relationship. I feel like this is happening too much. Can you come look at the equipment or can you come and support this nurse who seems to feel that she can never pass a baby. But I don't know if we can formally tell you looking at our ten sites what their refer rate is in the newborn population.

>> LINDA HAZARD: And then there is one other question about the protocol. Is it all inpatient.

There's a lot of discussion going on right now because our audiologists and our follow-up sites feel that it's important to have the baby come back. If they've not passed inpatient, to come back for one outpatient screening before going on for diagnostic. That's something we're also reviewing with our advisory council.

>> Jeff: Very good. Well we're about ten minutes over the hour time limit. Good questions. Great presentation Linda and Stacy. We're going to go ahead and conclude. Just a reminder that this webinar is recorded and will be available on infanthearing.org in about a week! So thank you all very much!

>> LINDA HAZARD: Thanks Jeff!

(Ended at 2:41 p.m. Eastern Time)