

ALYSON WARD:

OK, everyone. We will be starting our webinar in about four minutes regarding the Unite Newborn Screening Learning Community. Hang tight for a few more minutes and we will get going.

We will give it a few more minutes for people to join.

OK, looks like we are at the top of the hour. We are going to go ahead and get started. Welcome. We are excited to share these projects that these amazing teams have been working on for almost the past year. My name is Alyson Ward and I am the director of quality improvement at the National Center for Hearing Assessment and Management and have been overseeing this learning community.

I'm going to provide a little bit of the background and then I'm going to turn it over to our amazing teams. This webinar is being recorded. It will be posted for viewing on infinitehearing.org in the next few days. We are leaving the question and answer box open, so go ahead and jot in your questions as the presenters are going through their slides. Then we will actually hit the Q&A portion at the end of the webinar.

Please stay tuned for more, for your questions being answered later in the webinar.

This is a layout for today. I'm going to provide a quick overview, a little bit of background and how this Learning Community got started. Then we will hear from the Louisiana team, the Indiana team, the South Dakota team and the Michigan team. Then we will turn it over to the whole group to answer questions that are submitted through the question box.

A little bit of background. This is a HRSA funded project and it started with a lot of discussions between NCHAM which is the National Center for Hearing Assessment and Management, and we have served as the technical resource Center for all of the state and territory, any programs for the -- EHDI programs for the last 20 years. That is now moving over into Gallaudet University with the ICC grant. We are still heavily involved in the EHDI world.

We started having conversations with the Association of Public Health Laboratories about ways that we could start to work more together, more on the national level. One of the ideas that we had was to convene Learning Community. Like I said, we tried to brainstorm some connectivity ideas between EHDI, blood spot and critical congenital heart disease.

And we invited programs to participate. We wrote up an application to participate and there were a few different criteria that states had to meet to be able to apply. I know there were a lot of states that were interested in participating but getting that approval was a little challenging for some states. We did have -- ask for participation for one EHDI staff, one blood spot staff and a parent representative from each of the programs. As well as if there was a CCHP representative available, they were also welcome to participate.

The other requirement is that states needed to have the ability to participate in between August 2023 and May 2024. The remaining requirements were the ability to attend an in person kickoff meeting which we held in September in salt lake city. We had a great time, a lot of brainstorming. We met for about a day and 1/2 and had all sorts of learning and discussion.

That was followed by 4 virtual learning sessions where teams presented their data and work to date and we did that every other month. In the off months, we did individual team TA sessions. And states were also given \$30,000 to participate in the Learning Community with the requirement that parents had to be paid for their time at a minimum of \$25 per hour.

The purpose of the project was to serve as a way for peers to both learn and share, to Unite Newborn Screening programs together with the project aim of by June 30, 2023, the Unite Newborn Screening learning community will develop a document of promising practices for blood spot and EHDI collaboration.

What you are hearing will be the premise of that document so stay tuned for getting information on the details of what these teams worked on and give yourself some ideas of some collaborative ways that EHDI and Dried Bloodspot can work together in your respective states.

We used the model for improvement, MFI is what we call it sometimes, to guide our quality improvement work. You will see a lot of the language of aim statements, measures, and strategies and plan, do, study, act or PDSA cycle, you will hear from that from each team as we go through their slides. I will turn the time over to Dana, the lead of the Louisiana team.

DANA HUBBARD:

Thank you so much and thank you everyone for being with us today. We are so excited to share our experience and the journey we have been on. And hope that you are able to take something away that will benefit what you do in your state. Next slide, please. The one with the structure. One more back. There you go.

In Louisiana, we are set up through the Louisiana Department of Health. There we go. We had some organizational changes in the spring of 2023 that aligned both our heel stick as we call it, or Dried Bloodspot program, and our Early Hearing Detection and Intervention program under the same program. Newborn screening. Which as you can see, tears up from the bottom.

This opportunity was shared with us by the supervisor for both myself and (unknown name) of children special Healthcare Services, Cheryl Harris. We took it and fortunately we were selected to be a part of it. Next slide, please.

To do this with the Department of Health and the Bureau of family health, we were required to do a funding alignment discussion tool. For any new funding or new opportunities, we were required to fill this out. Here's a sample, on the left of what that looks like. All of the considerations we are asked to address, if anyone is interested in saying a more detailed version -- seeing a more detailed version that goes into the following pages that addresses all of the anticipated deliverables or support, please feel free to reach out to me.

The Louisiana team is composed of myself, as EHDI staff, (unknown name) who is an epidemiologist and part of the Dried Bloodspot heel stick staff, and to parents, (unknown name) who is our EHDI parent and Tiffany Allemand who is the Dried Bloodspot parent.

Initially, when we were considering our team selection, we knew that we needed to have staff from both EHDI and Dried Bloodspot so that was an easy step. When looking at parents, we realized how important it is to incorporate parents. This was such an exciting opportunity for that.

In Louisiana, there was some movement regarding congenital CMV last year in legislation. Journeys law passed in Louisiana for congenital cytomegalovirus screening and that parent, Journeys mom had joined us originally as our EHDI parent. Unfortunately, because of Journeys health needs she was not able to continue the process. But fortunately (unknown name) who is a long involved EHDI parent has hopped on board, and anyone who has worked with her, as she has been in this world for a long time, knows how good she is at jumping in and sharing her parent perspective.

Tiffany Allemand is already dried blood parents. Again, in Louisiana, heel stick. She is very involved with the genetics and rare diseases advisory Council and fortunately she was thrilled, she is smiling at that, thrilled to say yes to another opportunity to improve Louisiana. You are going to meet Tiffany a little bit later on.

To give you a quick snapshot, in Louisiana, there is 56,000 babies born. Those are the numbers for how many received a hearing screen and about how many received a Dried Bloodspot screening. Next slide. A quick snapshot, again, of newborn screening in our state, for Dried Bloodspot we screen currently for 33 conditions. Historically, there has not been any official collaboration with family entities. The heel stick

program does email blast providers and hospitals. And does post on the website.

The EHDI program, for those of you involved in the EHDI world, those are our one, three, six numbers for 2022. We do have some complement reworking relationships with our Part C system, early steps. And non-Part C programs. If you are familiar, we have the parent people education program, which is an outreach from the Louisiana school for the deaf. We also have a very active chapter of hands and voices that provides the guide by your signed support. -- Side support.

What did we hope to accomplish? We really wanted to empower Louisiana expecting parents by improving the newborn screening education that they receive prenatally. We wanted to demonstrate that by their participation in parent focus groups, and to increase knowledge of 50% or more based on pre-and posttest scores conducted specifically at West Jefferson Medical Center birthing class. Would you click, please?

Summarize, there it is, in a little bit friendlier language. Next slide. Collaboration. How did we decide what we were going to focus on? Both the EHDI program and Dried Bloodspot identified areas of priority concern. When we compared those, we selected a mutual area of focus, prenatal education. If you will click, it will animate for us. One more click, please. There should be one more animation. Maybe not. That's OK.

What steps did we take on that collaboration? We determined who was responsible, what tasks were required, when and where those interventions would happen and we used regular phone calls among our team members. Some examples of what that looked like where EHDI staff, we worked with the communications team within our Bureau to develop social media posts, drafted parent invitation letters, developed scripts. Our parents really helped with the parent friendly language for any communications we had that were parent facing. They helped us with that discussion guide for the focus group we will share later.

Dried Bloodspot really helped with communicate with and delivering newborn screening flyers to the birthing class facilitators. Also to highlight, at the bottom, when we look at our data, I know I'm going through this quickly and there's a lot of information on the slides, I really wanted to do information dumps so you can refer back to this later.

Focus groups were the big part of what we did. That was to determine what parents knew before, during and after heel stick and hearing screenings. Next slide, please.

How did we measure these things? There is a number of things listed but I wanted to highlight a couple. There were a minimum number of parents that we wanted to identify for each focus group. We wanted at least two parents who had a child identified through a screening, at least two parents that were identified through the EHDI process and at least two parents who delivered within one year in Louisiana.

We wanted to make sure we had constructive information that was gleaned from focus groups. This comes into play a little bit later. We wanted verifiable participants. And we really wanted to be able to incorporate parent feedback to produce a new prenatal education document. Next slide.

Changes that we made that resulted in improvement. If you will click, I think there is an animation. Thank you. We did hold parent focus groups. This is 1.0. We had different cycles of the PDSA. Our first focus groups were grassroots. We did a social media post and we had a really great response. We had two different surveys to help weed out participants and determine if they were eligible. Unfortunately, with the first round of focus groups, the majority were fraudulent participants.

The only way we realize that, it's kind of based while we were holding the focus groups, the responses were very interesting. And with the payment details that were submitted and we adapted the verification process and that kind of lettuce -- let us know where we stood. I'm happy to go into more detail one-on-one if you would like to email me or set up a time. For now, we moved on to our second cycle.

We adapted our verification process and identified eligible participants using our EHDl database and Dried Bloodspot database. We used the relationship already established with parents that we knew were enrolled in EI programs to invite them to participate in focus groups. We invited parents that agreed to participate in focus groups to ask their friends.

We conducted virtual focus groups at different times as well, to kind of make it so that any parent could participate.

I'm going to touch on this quickly. So, in pink we have the cycle one and in black we have -- (indiscernible) the green is the cycle to which is based on cold calls based on the information that we have from our database and it can kind of break into who said, "yes" at the first line and who ended up being eligible, verifiable, etc. all the way down to the end where we have shared information at the birthing class, pre-survey and post-survey.

And it ended up that cold calling was the best way that we reached families using the information from families already identified. We had 23 families that said, "yes" and 19 of them came from our database and four of those were referred from those in the database.

SPEAKER:

Just want to give you heads up that you have two minutes left.

DANA HUBBARD:

Perfect. We will skip the next few slides. I wanted to include them just in case anyone wanted to take a look at it for the next cycle.

In the end we realize a lot of things about parents. And these are forming our action steps forward. Overall, parents wanted to know more information during pregnancy, and they did not want to be alone.

So, in the end, we created a new board -- newborn screening fire available in English and Spanish and there is a link established where providers can access and send these to them. We could print three years worth based on our birthrates and we had support from the state Board of medical examiners who agreed to send an email blast to all of the physicians to raise awareness as well.

And this is just more information about that birthing class pre-and post. There were only three parents that actually did the pretest and one that did the post. I will hand it over to Tiffany who is our Dried Bloodspot parent.

TIFFANY ALLEMAND:

Hello! Our takeaways would have been time – deftly balancing work and life in the learning community. Opportunities, this learning community paved the way for Dried Bloodspot and EHDl to continue working in Louisiana.

We are going to really focus on newborn screening awareness month in September. We have three years worth of those flyers ready to be sent to hospitals and doctors offices, birthing classes.

Takeaways… That is me. But (Laughs) I enjoyed learning about the Dried Bloodspot program! More about that program and learning about EHDl because I'm able to share hands and voices and other program information with Deaf Soft and Hard of Hearing People in My Own Community and I Think It Is and I think it is an awesome opportunity to provide parents with screening information during pregnancy and how important that is. Family engagement and lived experiences relevant and necessary.

We built lifelong connections! In Louisiana and between the other states that participated, and of course, Alyson Ward and Mandy Jay. That is all. Thank you!

ALYSON WARD:

Thank you! I'm going to hand it over to Suzanne Foley, the lead for the Indiana team.

SUZANNE FOLEY:

Thank you so much for this opportunity.

Our team was very excited to participate. We had myself as the H IDI connector, we have Julie Swaim program and she coordinates the metabolic -- Abby Hall, she correlates the metabolic program in our step -- state and are EHDI parent was Julie Swain who has been with our staff for many years. She has an adult son that is Death and also Alison Breitbarth and her son was the first child in Indiana to be identified with Pompe after we started screening for that condition.

It was a great opportunity for us to learn more about each other and as we started discussions, primarily not just with our parents but with other parents in Utah, we realized that parents are not getting adequate information after diagnosis.

So, we were talking to many families who said that they walked out of appointments with nothing in their hand. And there certainly is a large learning curve in all of these conditions and so, we are responsible to get families to that diagnosis. But at that point, are they receiving adequate information?

So, our goal was to say that we would increase the number of providers who say that they have comprehensive information available to parents at the time of diagnosis.

We went back and forth about what does comprehensive mean? We defined it and we found that in order to do this, we had to target our providers. So, the EHDI targeted five audiology providers that diagnose or provide diagnosis after newborn screenings and the GNBS decided to tackle two disorders and those providers that serve for metabolic conditions.

We had good relationships with those providers and so we reached out to them and we knew they had -- we had their support. And then the EHDI and genomics team have collaborated many times over the last few years so we knew we wanted to do this project together and we had the support of our leadership.

So, how would we know that it was an improvement? We sent to those seven providers a survey that asked about the details of what a comprehensive material would be. And so we asked them to rate them, to give information, and what we were sensitive to was how we asked that question. Knowing that providers are busy, we did not want to be mean and say, "your information is not great."

But what we were surprised that -- at, is the majority felt that they were not providing adequate information to families. They felt like they did not have current resources, state and national, to provide to parents at the time of diagnosis.

And so, our data was the baseline of our survey and then as we engaged more providers, we will be giving them this pre-survey and certainly post survey to see if they feel like the materials they are able to provide our better, or more comprehensive.

So, we sent the provider survey out. What we also did was we built a grading rubric and evaluated the materials that providers sent in. So, for example, Julie, and EHDI parent, evaluated all of the information provided by the metabolic providers. And then Allison evaluated the information on Death and hard of hearing because they did not know much about those conditions and they were trying to mimic a new parent with that diagnosis.

The grading rubric is here and we had several questions that we had to ask. Was the information in multiple languages? Was it at an appropriate educational level? Was there website information? And then we graded that. And the goal was that we would go back to those seven providers with the rubric and that information and say, "here are some areas that we feel need to be improved and we are here to help you with that."

So, we can either revise what you have or we will work on new materials to share with all providers in the state to make sure that it falls under some of the rubric areas that we are identifying.

OK. And Abby, I think that is you!

ABBY HALL:

Yes! Kind of going back to what Suzanne was describing, our PDSA a cycle. Our plan initially was, our question was, what materials do providers currently have and do we/they think they are adequate? Our assumption was that providers did currently have materials but however -- however, we were pretty certain that all of the materials did not meet the needs of all of their patients and families and could use some improvements.

So, the do, as Suzanne described, was to do a survey and we sent it to both audiologists for the hearing screening and also metabolic teams. We have two in Indiana. And we had dietitians and physicians and ideologists all complete those surveys. And some of the questions that were on the survey was, do you have materials that you handout? Are they available in different languages? And is the information appropriate for different cultures or literacy needs? That was just a few of the questions.

The survey responses. We had 10 in total. 80% of the responders did say that they already had materials that they handed out. So, that was a surprise. And there was a variety of different next -- responses if they were meeting different cultural, literacy and language needs. A majority of the responses did say that they were not able to accommodate all of those needs.

Other areas of need identified were access to materials online, consistent -- consistently connecting families together with like diagnosis, and 90% of the providers felt like there materials were not adequate.

So, the act was the evaluation of the providers materials. As Suzanne described, we developed a rubric to kind of grade the materials based on what we thought was appropriate with all of our clinical experiences and most important, with the parent experiences and knowing what parents want and need at the time of diagnosis.

So, our takeaways and next steps. Our next step is to meet with the medical teams. So, we need to review our evaluation results of their materials and also provide them with the new resources and educational materials that we have developed.

So, our goal is for them to be able to use these in their clinic settings as needed, and even make some of them customizable if that is appropriate. We are at least going to provide a one-page resource per condition and an FAQ for families and also a state and national resource guide.

We will kind of provide – or we found a point on the rubric that we developed, we also developed a resource checklist so that this will allow them going forward, if there are any new materials that are brought to them, or anything that they find, they can use this checklist to kind of grade those materials to see if they do meet the needs and are appropriate for their patients.

We are going to make these resources available on our website. This is for both the patients and the providers. And, we hope to establish a process for these resources to routinely be updated and revised with kind of our team to help out because we know that the clinic and the providers, that is one of the reasons why their materials are not as adequate as they could be. They probably once were. But, we will help evaluate those and keep that going to help them out as well.

We also aim to scream for more metabolic conditions and we have started with two. PKU because it is the most prevalent and (unknown name), because that is a disease -- a (indiscernible) are parent is familiar with. We are going to add those materials.

We also want to increase access to more parent to parent groups and improving connections at that local and state level because that was something definitely missing from the metabolic and Dried Bloodspot team. Where the EHDI team has wonderful resources and able to stay connected and have parent to parent support.

One of our biggest takeaways from this project was working with other states and learning about their programs and the parent perspectives that are invaluable.

I think Allison… Are you there?

SPEAKER:

You are on mute. You guys are at 10 minutes. You have 10 minutes left.

ALISON BREITBARTH:

I'm going to talk about the tracklist that Suzanne mentioned. This is what we used to evaluate all of the materials we were given both from metabolic as well as from the EHDI list. We went through this checklist and did it with all of the materials that we received. We wanted to make sure things were in caregiver friendly language and were not too technical. We wanted to make sure our parents were provided materials in writing at the time of diagnosis. That was something we asked the clinics. We wanted to make sure the materials were at 1/5 grade education level so they were able to be understood by all.

We wanted to know if they had materials with state and national resources. If they were giving those two families at the time of diagnosis. We wanted to know how updated their websites were. As well as if the materials were available in different languages. And what did they have on their websites. And then, do you have a variety of websites available at many life or diagnostic stages? Are there different materials that are throughout that journey that are available for families? So a five-year-old would be getting different materials versus a very young child.

Do you have contact information listed? That was something we realized that you might be getting all of these materials, but when a family goes to contact, do they have a way to get back into contact with you? Is that easily found on your resources? And making sure the resources they are providing are clear, not blurry, and most importantly, they are not outdated. We wanted to make sure everything was within the last 2 to 3 years.

And we evaluated if we thought they were giving too little information or too much information. We did that with all of the materials people were given. Next slide.

Right now, what we have done is we are making a big list of all of the state resources for conditions as well as national resources and websites for conditions. As well as patient and parent advocacy groups and places where families can find community and financial support. We started this with PKU and Pompe and are combining all the resources together and we are going to use that to put together our one pager that clinics will be able to have available to give to clinics -- families at time of diagnosis.

It was really great for us all to be able to come together and work on this project, both with EHDI and Dried Bloodspot as well as with the parent perspective from myself as well as Julie. Part of my, me as grants giants, that is my nonprofit, that is my son, Grant, part of the nonprofit, something we do is help connect families together at the time of diagnosis. That is one thing our clinic has been able to give families as a resource who receive a diagnosis and we hope to see more of that in the metabolic world as well. Thank you for the opportunity for us to be able to collaborate on that project.

ALYSON WARD:

Thank you so much, I appreciate all the work you have done. I'm going to turn the time over to Shelby and South Dakota.

SHELBY HINTZE JEPPELSON:

Hello. I want to say thank you so much for allowing South Dakota to be involved in this. I know that each state has a unique scenario, South Dakota included, but this was a great opportunity to be involved in this learning community during the really impactful time, during a time of change in our state.

Our team is myself, I am an assistant professor of practice in our school of health sciences. And our University of South Dakota. I'm a part of this because I'm also the project director for our state's HRSA EHDI grant. And representing our newborn screening and Dried Bloodspot program is our South Dakota Department of Health. This was originally Bernadette, who was the newborn screening program coordinator and then we had changes occur. We had a parent representative for EHDI, the parent of a child identified through the newborn's creating process, and then Mandy was also the parent of a child identified represent in the Dried Bloodspot program.

We were able to reach out to these programs – my parents because they contacted our state agencies with the intent to improve the screening system in our state. They understood the process, understood that post identification support in the state, really could and should be better for other families due to the experiences that they had. We knew they were already great advocates for this. We were able to find Mandy, because she is on our newborn screening advisory committee. We were connected to her through our Department of Health. And with Brad, through our state EHDI chapter, since they identified him as a parent who had been in contact and done great work.

And then USD had prior experience working with parents or the EHDI grant and we worked with our hands and voices chapter and the Department of health had a long history of working together and specifically our relationship on EHDI effort through the last decade.

Two lineup -- lay out what newborns rating at South Dakota looks like, we have about 12,000 births per year and 99% of those do receive newborn screening through the dried blood program. Right now, in the state of South Dakota we do not have critical congenital heart disease included on our newborn screening panel. Our metabolic or Dried Bloodspot program is run through the State Department of health, like many organizations, there are many different layers and levels and offices that are part of that program.

Some of that work is contracted out to the state hygienic lab in Iowa. And also to the Stanford children's specialty clinic. So diversifying who has those different components of that program.

The hearing screening through the EHDI collaborative is the University of South Dakota and the collaboration we've been in with the State Department of health for about a decade now. We also have a very strong parent and family component to our newborn screening program. That representation on the advisory committee and family to family support organizations, we know we can always go to for any questions that we have, how to make things inclusive to include parents.

Those four organizations that are in italics, are what we consider four of the key agencies responsible for the newborn screen process in South Dakota. Our original aim was by… Next slide.

By May 2024, to have 50% of our responding providers and parents, with about a 75% response rate expected, report informative communication and notification. At the time that they were called and told or possibly in a breathing facility, told that their child was referred to hearing screening or had a presumptive positive for a newborn blood spot test. This was determined by responses that we would get from survey calls administered by the newborn's creating staff at the Department of Health. Also tracking visits to the website, information related to us -- relate to us and how we can identify that.

We chose the same because we had some really great input from the parents on the team, realizing that of course newborn blood spot program and hearing program really focused on the child. Each child in the state that is born is a part of this. The parent experience is what can have an impact on child outcomes so we wanted to make sure that parents were getting the information that they needed, that they found to be helpful or informative so that parents were empowered to have the information they needed to understand

the child's condition.

This was relying on the Department of Health team member to make the call as they would have access to that information. The intent was to call those cases that would have been identified in the prior month, to give those parents and providers a little bit of time after the event but still near enough to it to recall what happened.

And noting throughout, we use the word provider to signify the physicians or the other healthcare providers that may be working with that family and child and we used the word parent but we also understand that this could be anybody who is the newborn caregiver.

Some of the measures, looking at we have responses from those providers and parents, we used survey questions to do that, looking at number of births per months. South Dakota has about 12,000 births per year, around 1000 per month and we were able to look more specifically at what were the number of presumptive positives and those who referred the hearing screen each month so we could identify what was a reasonable number of those individuals to get in touch with.

And also making some changes to the state newborn screening webpages. And from that, being able to track how many unique visits and unique visitors. We are looking at the site -- visitors were looking at the sites during the Learning Community time period from September until May.

Some of the strategies listed here, some of the questions that we asked or anticipated asking of providers and parents, what information they received, if we needed to prompt them to determine where they were receiving or giving -- given information related to websites, emailing, and verbal information and to the key part was if the information was useful or helpful, and knowing that really can be dependent on the individual but knowing that they are all coming from different places. From that, we can determine if we are missing any key materials.

And listing a few of the websites that we included on the state Department of Health site and also our EHDI site to try to cross list newborn screening of blood spot and hearing materials, to link the two together. Next slide.

We created some strategies, some key points for audiologists, or those who may be identifying those who are Deaf and hard of hearing. We went to several different events throughout the state as a unified entity of the EHDI and Dried Bloodspot, providing materials on both, talking to not just the general public but a lot of the other vendors at those health and wellness fairs. Trying to tell the community health workers, all of the other folks who work with individuals during pregnancy or shortly after, to know where they can reach out for those materials.

We went through many different PDSA so I have a few abbreviated ones here. First was giving guidance to the providers on what information they might be providing families, ideally through that website being one central and easy to find location. From that, doing some mock discussions or calls with others on the team who may not have been as familiar with the other program, we determined that it was very difficult to remember some of the complex names, so we changed our strategy to tell those people to spell out or repeat or have the parent or caregiver right down the name of that disorder and not use any abbreviations because it was difficult for us to remember it, if we wanted to go find it again, or for those parents who might need to relate that information to other healthcare providers.

Next slide. From that, we moved to trying to make those contacts with the parents and providers. From this, we had a staffing changes the apartment of health at that time, we determined we were not able to make those contacts in our anticipated initial attempt in trying to think of if we could get in touch with those individuals another way but that was not available either.

So we made a change in our aims. Then it was to identify 75% of our partnering organizations and that they agreed with the statement that when communicating with us they were able to learn more about the

process and really understand the impact and the cohesiveness of the system.

From that, we put together a survey to ask those key organizations and a few individuals from each organization, that was an 11 question survey from all of those who responded, they agreed that they understood or that they learned from our communications. Those communications came from, I tried to count at best I could, 35 different meetings we had from a six-month time period, December until May, to work with all those key organizations, with the staffing and structural changes to ensure that everybody understood that there were multiple partners included in this process.

And some of the things we created were three public facing materials that we developed as EHDl and the Dried Bloodspot program together.

This is just showing what a few of those questions were. So, trying to identify if they understood the importance of the cohesiveness but also looking at they knew that their organization was a part of it and understanding that there were multiple organizations as well.

And then, just determining if they knew that there were so many different entities that were a part of the newborn screening process, and it was great to know that many of them understood that.

Next slide, just to go through a few of the products so – we were able to cross list the newborn screening on each other's websites so that we could share that information and have that go back and forth.

And then an exciting, and extremely exciting piece in South Dakota is that the Department of Health has added newborn health screening to their newborn screening panels, something that a number of people have been working on for decades in the state. So, that was actually on Monday that that went into effect! Now all babies born in South Dakota have the initial newborn screening requirement before leaving the hospital.

That is been very helpful in creating all of these joint materials so cut one of the joint materials were these (indiscernible) just made some for social media, some provided to parents, and also some for providers.

With that, the newborn hearing screening program materials from the department of health were updated to include hearing. So, another place to show that this is a unified entity.

End of note here, it is small, but Mandy, our parent representative, that is her daughter whose picture and story is represented here. So, you can always take a look at our website to see that in more detail!

Our takeaways. So, through all of these changes, it was really great to learn about each other's different programs. So, frozen -- from that, knowing why it was so important to have the cohesive process, who to contact across those different agencies and from that we plan to work on you now find newborn screening manual or materials to provide to all of those different types of providers that work with families when they have -- then they have that informative information to provide some parents have the information they need that is useful for next steps.

And also looking at exporting opportunities for more birthing hospitals and providers to provide information into the Newport screening system so that they have increased by an end can have input on the process for them.

One of the things we had the opportunity to do was have Mandy, the parent representing the Dried Bloodspot program attend the EHDl conference and from that, seeing how important it is to have parent support across any of those types of conditions that families deal with. So, knowing that the EHDl has great programs in place but also to facilitate that with the Dried Bloodspot families as well.

And very excited to take lessons from all of the other states and use those in the future as we move

forward.

ALYSON WARD:

Thank you so much, and that was excellent. Thank you to the South Dakota team! OK. I will turn the time over to Gina Cooper, the project lead for Michigan.

GINA COOPER:

Thank you.

OK. I am Doctor Gina Cooper, an audiologist in the HDI program coordinator for the state of Michigan. I am joined today by my colleague, Kristen Thompson, who is the newborn screening program coordinator and together, we are going to share our project that we worked on. We will give you an overview and some of our outcomes and next steps.

I will turn it over to Kristin to kick us off!

KRISTEN THOMPSON:

Sounds good, thank you, Gina!

So, first we will start with our team. But first I want to explain a few things about Michigan's newborn screening and EHDI process. We have two separate programs that cover all three aspects of screening, including dried blood spot screening, congenital heart sees screening and hearing screening. Dried blood spot screening and CC HD screening exist in the new program but hearing screening is through the hearing detection -- through the Early Hearing Detection and Intervention program.

While both programs are part of the Department of Health and Human Services, they are overseen by different bureaus in different divisions. So, on the slide here you can see our project team. We had representation from EHDI, epidemiology, newborn screening and also to parent representatives. One representing a Dried Bloodspot condition and one representing early hearing loss.

So, just getting started with how this project began, Michigan's newborn screening and EHDI program had a history of collaboration and for the 12 months leading up to this project, newborn screening, CC HD and EHDI representatives met quarterly to discuss individual programs and brainstorm and execute ideas for collaboration.

So can we build on this momentum and looks for opportunities in our community.

It was determined that a comprehensive training program did not exist in Michigan for community birth providers interested in learning more about newborn screening. For reference, Michigan has about 100,000 births every year and of that a proximally 2% of the births are community births. This percentage is expected to increase.

The aim of our learning community project was to increase the number of babies born between January 6, which was the date of our first training, through May 10, the date of the data collection for this project to newly trained midwives that received Dried Bloodspot, CC HD and and BHS to 50%.

And we wanted to increase the comfort level as measured on a five-point scale of newly trained midwives on performing all three of these types of screening. Creating a comprehensive training program for community birth providers.

The two trainings were conducted, one was in person on January 5 and the second one was virtual on March 5. All participants were given a pre-and post-survey to assess progress in screening comfort levels. Participants rated comfortability in collecting each screen on a scale of zero – not comfortable, to five – very comfortable.

In addition, screening rates for participants were tracked and compared between pretraining baseline – all of 2023, and post training project. – Which was from January 6 to May 7.

The learning objectives of the training were to enhance the knowledge of breathing attendance knowledge and recognize the importance of newborn screening and commit to screening all infants of births in which they attend. And ensure prompt follow-up and reporting of results for all three screening components.

Topics on various aspects of this screening techniques were included, for example, we reviewed blood spot screening and follow-up, newborn screening hard ordering and payment, newborn screening parent education, and overview of the EHDI program including reporting and hands-on screening techniques. And CCHD screening and reporting of data.

A parent video was created and shown as part of the training that highlighted the importance of newborn screening in the homebirth setting. I will put a link to this in the chat if anyone is interested. Lucy's hearing loss was detected at a homebirth as a result of hearing screenings.

GINA COOPER:

Right, this is Gina Cooper speaking. I will talk to you a bit more about the results that we saw and conclusions and next steps.

So, as Kristin mentioned, we did two trainings, one was a day long in person training with lecture in the morning and skills, hands-on training in the afternoon. And in March, we did a virtual training. We had 25 total participants. Six teen attended our in person training and nine attended our virtual training.

As part of this, we had to create a lot of material, presentations, get workstations together, so, a lot went into pulling these off. Next slide.

So, our training was targeted towards new community birth providers. So, we worked with some new birthing centers that were looking to start up. And what you could see is our pre-and post information. So, on the left is the number of participants who have documented birth attendance prior to training.

What you can see is that four of the 25 attendees had documented birth attendance prior to coming to our training. After the training in our preliminary data collection period, we had six of the 25 who had attended births.

The reason I bring this up is because it is important to highlight – I think we lost it – one more! They go. Thank you.

It is important to highlight that one, we reached our target audience. These were new providers. And two, we still need a lot more time to really make any conclusions with our data with only six of the total attendees being present at birth that we can analyze the data.

So, our sub aim as Kristin mentioned, was to improve the comfort level of performing types of screenings for our attendees. You can see that there are numerical values on the left and the blue and orange bars represent pre-and post ratings. So, we did calculate an average comfortability rating for each type of screening. And happy to report that we did see an increase in self rated comfort level of performing all three types of screens following the training.

So, now let us look at our very preliminary data and as a reminder, these are just those small percentages of attendees who had been present for births before and after.

The color bars represent the percentage of screens performed by providers out of the total number of births that they attended. The blue bars are our baseline and these include 30 total births attended by those four providers.

Our target was to community providers so we expected the number two below. The green bar is our very preliminary outcome data for 2024. So again, this is from those six participants and they had attended a total of 29 births.

The other important thing to call out is that in these graphs, we are comparing all of 2023 to just the January through May 7 in 2024.

So, knowing all of that, are we seeing an entrance? And the short answer is yes. We are starting to see trends emerge. What you can see is before and after training we can see an increase in the screening rates for blood spot and cc HD.

Hearing screening remained essentially flat but was slightly decreased from 53 to 52%. And all three screens again, essentially flat but we saw slight decreases from 46 -- to 47%. Our aim was to increase all three screens to 50%.

Interesting trends. What do we make of these? Again, very early in the data collection. And one of the things to take away is timing. It is likely to soon from the training to really measure significant changes. You know, for example, a new midwife still needs to follow a patient through the birthing., Etc. so we might not see data for another 9+ months.

We also think that this might be a sign of the things to come. One thing that we know is blood spot are typically our quickest to report due to the time sensitive nature of the specimen. Followed by CCHD and we are seeing good trends with our screens that are quick to report.

Hearing tends to lag in reporting behind, we still have a manual process for faxing in from community birth providers.

The other thing that the team talked about was also related to access to hearing screening equipment. At the time of pulling data, the birth providers at the birthing center had not yet completed an application to obtain hearing screen equipment.

What conclusions can we leave you with? What we think is that combined training can increase the average self-reported comfort level in performing all three types of screen. Results from our small number suggest that training new and currently practicing midwives may help improve some screening rates. Improvement can be limited by direct availability of hearing screening equipment. Ultimately, time is needed for new midwives to establish their practice and begin offering screening. As well as more time to report.

We look forward to giving you more information later. As we are able to collect more data. Next slide. We did offer two different training formats. We will be interested to see if we see differences based on in-person or virtual. We will also look to changing the way that we collected comfort level so that we don't have to use averages. Is there a way that we can be identify information so we can -- de-identify information so we can get specific improvements.

Another take-home was that we have opportunities to customize our messaging for community birth populations. They have different things that are important to them, for example, as a result of this, there is now updated forms for parents to request the blood spot to be returned to them, that was identified as important by some of our attendees.

Like the other teams mentioned, there are such good, collaborative benefits that happen beyond just the scope of this project. We look forward to continuing to collect data as well as have so many ideas for new projects like reducing reporting time, creating a dashboard for community birth providers and increasing access to equipment.

I think that is it. Thank you.

ALYSON WARD:

Thank you. And all of the Michigan teams. I'm going to turn the time over to Mandy Jay who is my colleague here at NCHAM to fill the Q and a questions. Mandy has been incidental in writing this in community as well. Take it away.

MANDY JAY:

Good afternoon, everyone. If you have questions, please type them in the queue and a box. I will sort them by who they go to and we are going to start with Dana and Louisiana. The question is, were home birthing families included in the focus groups?

DANA HUBBARD:

That's an excellent question. We did not rule out anyone based on location of birth. What we did is we went back in cycle one, we did a social media post. Anyone that birthed a child in Louisiana in the last three years was able to participate based on that. For cycle two, we used information in our databases and looked at any childbirth in Louisiana in the last three years. So we did not look at where they were birthed that. For some of that information.

MANDY JAY:

Thanks, Jana. -- Dana. The next question we have was geared towards Indiana but anyone can answer, I would be interested in hearing it from anyone. Did you see any responses from providers and parents that were not in alignment? How did you proceed?

ABBY HALL:

I can answer for Indiana. No, we really didn't. We were kind of, we have good relationships with all of the providers and teams from past experiences. We also know that we were coming in to say hey, what you have might not be the best, can we help you? So we were treading lightly but everyone was very open and… What we thought and how the providers reacted was very online together. We all agreed that a revamp was needed.

MANDY JAY:

Great, thanks. Anyone else want to comment on that question about responses from providers and parents that were not in alignment when you were asking questions?

OK. I will keep going. If someone wants to come back, they can. The next question is, did each state offer a stipend for families? If so, was it a standard amount for the project or was it a state to state decision?

We did offer stipends for families, go ahead, I will let you…

DANA HUBBARD:

Thank you so much. This is Dana with Louisiana. We offered stipends for families participating in the focus group. We arrived at the amount just through discussion with Mandy and the parents on our team. We broke out by if a parent completed the initial demographic survey, also if they participated in the hour-long focus group, and then there was an additional amount if they completed an evaluation for us afterwards.

MANDY JAY:

Thanks, Dana. For the broader Learning Community, the parent family representation from the dried blood spot program and the programs were given, were paid for their time to participate in this Learning Community. So that is the broad picture. But does anyone else have questions or answers around stipends for families in the work that you did? People outside of your parent reps?

SPEAKER:

It is Tiffany from Louisiana, I wanted to say something to touch on what we went through, any other

organizations or states that want to do focus groups, be very careful posting to social media. That's it.

MANDY JAY:

Thank you for sharing, Tiffany. Yes, Louisiana had a great response. But they had some clean-up to do because of the fraudulent responses. Any other questions?

DANA HUBBARD:

This is Dana from Louisiana. I have one more addition to the stipend for families. Mandy mentioned that parents that were part of each team were compensated for their time and their experience. One thing we incorporated into ours was an additional -- initial stipend for respite care or whatever type of care they needed for their child or family when they were asked to be away in the initial kickoff.

We wanted, we did not want it to be cost prohibitive to any family that needed to secure care for their child.

MANDY JAY:

Thank you for adding that. I want to thank all of our state teams, didn't they do a great job, they worked so hard and there is so much to learn from all of their experiences. This is your last chance to ask a question. Unless you have something else, say a comment, this says thank you to all presenters, your work is admirable, and it was great to see the variety of projects began and accomplished through this learning community. I want to focus on the begun because many of these projects will be ongoing. As they learn some great things.

Here's another question, were these studies conducted in other languages to ensure cultural diversity?

SPEAKER:

I think that had to do with some of the focus groups and prenatal classes.

DANA HUBBARD:

I know in Louisiana our team itself was diverse. (unknown name) who is with the heel stick program, is Vietnamese, (unknown name) is from Venezuela, Tiffany is from Louisiana and I am from all over. We had a diverse representation on our team. But part of (unknown name)'s position with the EHDI program and with hands and voices is she works with our bilingual parents. So we were able to capture some information for our Spanish-speaking families. And then reproduce our newborn screening document which is also available in Spanish at this point.

If you look at the slides after the fact, you will see we did give a breakout that… I think three of the families, maybe for were bilingual families who also spoke Arabic. It was an interesting mix.

MANDY JAY:

Thanks, Dana. We have a question asking if the doctors in Indiana were welcoming to the information shared?

ABBY HALL:

Yes, I got off when I was talking, I meant to say they were excited for it and were very open to what we were doing. And thankful that we were able to do it. I previously worked with the team directly and Allison is one of their patients as well and Suzanne works with the audiologist very closely. We do have really good relationships with all of the teams that we worked with.

MANDY JAY:

Thank you. Suzanne, did you have something to add?

SUZANNE FOLEY:

I was going to say that the providers, I think, were open based on how we approach them. It was a very collaborative project and we were trying to help all providers define what was comprehensive.

We acknowledged and they reported that in a busy clinic day, updating materials is not something that people have time to do. I think that was acknowledged by us as providers in our world as well. And trying to say, we are really asking for this information so that we can help you with providing better information because we know you are busy and this is a hard thing to do.

MANDY JAY:

Thanks. OK. I think we have answered all of the questions. If you have more questions, feel free to reach out to one of the presenters or Allison or myself and we are happy to connect you. This webinar will be posted online infinitehearing.org in the next week or so.

Thank you so much for taking the time out of your day to participate in this webinar. We hope that you have a great day.

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