>> Good afternoon. Thank you for joining us to adjusting EHDI systems of care to timely follow-up services. I'm Daphne Miller with the Virginia EHDI program and for this session, it will be Deepali and Parker, our epidemiologist. Today, the learning objectives, we will provide an overview of the EHDI systems in Virginia. A discussion of EHDI IS, and we will interview enhancements of EHDI follow-up overtime and evaluate the impacts of the automated follow-up.

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Expansion of EHDI, as many of you know, we have expanded over years, from the implementation of newborn screening 2000 in Virginia, it has been 23 years, oh, the expansion was fueled by frustration due to lack of staffing, turnover A and not enough time to communicate what we wanted to communicate to families. So, a lot of this expansion work happened because there was a need for us to automate so many things, because we didn't have the staff to take care of all of the things we wanted to do.

COVID made it more pressing for us to get these things done. So, I'm going to tell you a little bit about the Virginia EHDI. In 1999 is the beginning of EHDI systems in Virginia, and that was implementation of legislation. So, in 2000 is when we started to follow up on children. And the only results we received were the children who failed so, we didn't know what we didn't know.

In 2007, our system, which is Visits was our electronic database was put into place. That was a database that captured the majority of our reports, our diagnostic reports, our screening information from hospitals, the only issue is those reports were sent to the department of heat or EHDI and we entered them manually. Overtime, having the automated system supported us in having less staffing for reporting, and you know, more time to do other things like follow-up. In 2010, our external stakeholders, which are like our hospitals, received access to our system. That allowed for us to have accurate reporting, real-time reporting and less data entry from the Virginia Department of Health.

The expansion of EHDI to users. So, in 2010 is when we had expansion to hospitals. Hospitals have access to our system. In 2012, audiologists had access, in 2014, we got access for early intervention. 2019, we had family-to-family who had access to our system and in 2022, with a lot of work, we finally have access for PCPs.

Now, I will tell you PCPs have been very difficult for us to get in the system, but so far we're excited we have 100 in our state who have signed up to get in the system. In order for us to move forward with automated system, we want to remove some of the letters we spent a lot of money on to PCPs, so we're hoping we can automate the system soon to send to letters to our PCPs through e-mail or through our system.

EHDI-IS enhancements. Let's start with hospitals in 2010, they are reporting on all children now, so we're getting all of the information and they are able to enter the information based on a pending lab on that system. They know all of the children born in the hospital, they are able to enter on. In 2012, due to a hospital site visit, at the hospital site visit, you know, a lot of times you get suggestions from people who are actually doing the work, hearing screeners or whoever is entering the data, so one of the questions that is asked, how can we improve this system?

So, the feedback was give us a pass-pass feature, so we no longer have to enter all of the data for children we don't need to follow. So, we entered a pass-pass feature, so they didn't have to enter data on children that didn't need follow-up.

In 2014, when audiologists entered our system, they entered diagnostic reports, so no longer did we have to enter the report and call the audiologist and saying we're missing information on this report or we're trying to determine the report, so we no longer have to guess or call them and have communications with audiologists and say, hey, we need a report from you. That was helpful, because they can enter their own diagnostic reports.

In 2014, additionally, we had an automatic referral to the EI. So, when the audiologist enters a referral to the child, it sends an e-mail to EI. Now, EI knows they need to go in the system, because of course, they are busy. They don't have time to go into the database each day, when there is a referral, they get an e-mail from us saying, hey, you have to go in the system. They go in the system and they get all of the information they need on that child.

Before that, when a child was referred, we had to call them. So, we take all of this time, you might not get in touch with the person right away, so you are calling and calling until you get someone and then you have to give them all of the information over the phone. That gave us time back, because we no longer have to do that.

In 2016, parents started to receive to letter with risk indicators on it. If a parent got a letter from the Department of Health, your child has a risk indicater. They don't know what the risk indicater is. We're going to work with our team to make sure the risk indicater on to letters. So, now it can handle putting any risk, they have five risks, it will come up there they have NICU greater than five days or whatever it is.

2019, many of you remember we had the share plan of care. The share plan of care was put into our system electronically, because we knew that even though we could create these papers and send them out, it was best for us to have something electronically for providers. Actually that allows audiologists, PCP as well, family to family to have access. That information that is entered is on genetic counseling, if they have seen an optologist or went to the ENT or got enrolled with family to family. So, we collect all of that information in our system.

In 2019, we had an audiology focus group. The thing that our system used to do, it didn't determine if it was a rescreen or diagnostic. Getting the audiology work group together, we went through so many variables of what could be, right, so we did an algorithm where you put in -- if you put in temperature -- temonomitry, our system did not have to guess. They did a lot of testing and audiologists went back and forth agreeing, is this considered a diagnostic or not. Then we did it by age, if a child is 6 months old, what is a diagnostic compared to a child who is 12 months old.

In 2020, the last thing you might know, in Virginia we have targeted CMV. The CMV module was developed and entered into our system. Now you, there's are CMV viewers that may not be the same as newborn hearing screeners, but they can go and let us know the results or print their information and send the form to the lab, so they can get the CMV results for the child.

So, that's where we are with our enhancements to our system. I'm going to pass it to Deepali who is going to talk about our enhancement of follow-up.

>> Deepali Sanghani: Can you guys hear me? Okay, good. Thanks, Daphne for laying out the progression of EHDI over the years and how we enhanced our system to capture the appropriate data. I will just highlight what we've done in respects to automated our follow-up and how we used our system to do that.

So, we know that, you know, there's a growing use of technology and families are having babies at very young and a lot of times glued to their phone and they like to use their phone as a resource, as opposed to reading letters or things we mailed them. We started automating back in September of 2018, we automated our system to send text messages. So, any time a letter was generated in our system, it would automatically send a text message to the family and say, hey, your child needs follow-up. Please call us for more information.

So, that was a good thing back in 2018, but then we realized really quickly, hey, if these families text us back, how do we capture that? In 2019, we turned around and added a feature where families text us back, we have the ability to capture the text backs in the system, so we can see what we sent them and what they responded. A lot of times, families will say, my child has already gone back. We had an appointment at this place.

In 2020, we realized we had one brochure, so it was just this brochure that babies were getting or babies were getting in the hospital, and the nurse had to kind of check whether they passed, failed or passed with risk and fill all of the information out. Well, in 2020, we realized that the information is not being accurately relayed and that is a concern sometimes at the hospital, so we revamped our brochures and they are in the back. We have results-specific brochures now. There is a brochure for fail, miss, passed with risk, etc. So, we did that in 200.

And then we developed a short video that accompanies the brochures, so we started texting that video out to families in 2021. It is a one to two minute video, it is very short and tells them what they need to do next. Then we added a Q R code to the videos on our brochures just recently last year in 2022. Now, at birth, they get the brochure, they can scan the QR Code and view the video or read the brochure, whatever they prefer.

Sorry. There we go. That's what we've done so far, and now what are we going to do -- what are we doing right now and what are we doing next? When we shifted to tell telework, we can't communicate as much, and we needed a centralized system for all of our incoming calls and for everyone to see that information. So, in 2022, we were able to develop an interactive voice response system, and what that is, we have one central phone number and we have options for parents and professionals and I will show that in a little bit detail in the next slide.

And then we started automating robocalls, so when our families get a letter and the text message, we also sendal robocall. It is a quick call and I will play one for you in a few slides that tells families, hey, your baby needs follow-up, please call us. Then we started to have on demand SMS. If they respond and it says my baby went back, we can say where did they go and get more information without calling the family. We can respond with a text.

And then we moved to daily letter generation, because we know that it is really important to get that information out quickly, and that allows families to go back sooner.

And then moving forward, this year what we're working on is incorporating outgoing calls, so the outgoing voice response system last year allows us to capture the incoming calls in our system. Now, we want to capture all of the calls we make to the family, so that is what we're working on this year and we're going to have interactive dashboard. Our team can view it in one place. No matter where we are, we can pick up on someone else's calls or follow up and track it with our interactive dashboard.

So, this goes over, you know, what our interactive voice response system looks like. The blue is options for parents, so we have several staff, some of them do CMV follow-up, some do audiology follow-ups, some do initial. We have the similar options for professionals based on what they are specializing in. In the top, it shows -- it is hard to read, I apologize. The top on the left, it shows the date and the time the call came in. There is a big, white box in the middle. What would be there, we had to take that out to maintain confidentiality, but what would be is the incoming caller's phone number and what staff on the team should receive that call based on the option selected. And then there is a play button that we can listen to the voice mail that was left or listen to the conversation that was had with the staff and the family. and in the middle there is a transcript of that call.

We use this is a lot for QI, because we can listen to the calls that were made with the staff member and say, hey, you know if this is the kind of things we can improve in our follow-up, how can we improve the messaging that is given to families? And then on the right, is the individual call that we can look at. You see again, the transcript. You can play it and associate it with a specific child. So, you click on that and put in an ID number and it can be in that child's record.

Sorry, this is hard to move. And then, so the robocalls that I was talking about earlier, I will play one of our robocalls. They are very short.

>> Please send us a text with a date and location. For more information, visit our website.

>> Deepali Sanghani: Start it over.

>> A reminder to schedule a hearing screen for your baby. If your child has already returned, please send us a text with a date and location. For more information visit our website or call us at 804-212-3020.

>> Deepali Sanghani: So, just short, quick call that tells them why we're calling, who they are and where to call us back. And I will see if I can do captions on this. This is the short biteable video we developed. I'm sorry. I'm going to try to get the captions. Oh, I can. Yep.

>> Congratulations on the birth of your new baby. The next thing you will want to do is set up an appointment as soon as possible for your child's hearing test. Visit our website at vdh.Virginia.gov/hearing to assist in finding an audiologist in your area. When making an appointment, be sure to schedule enough time to test both of your baby's ears. As always, feel free to contact the Virginia EHDI program at 804-864-7697 with any questions or concerns.

>> Deepali Sanghani: That's it. Thank you. And then, so we have several of those videos for a child who fails their hearing test. And again, short one to two minutes each, and on the right, you can see just an example of some of the text messages that we're able to send. The top, it just says this is the reminder to schedule an appointment for a hearing screen for your child and we try to put, if your child has returned, please reply with the location and date. And then we link them to our website and a call back number.

The bottom is, we recently incorporated where if the hospital lets us know where the family is going to go back, we can send a reminder text message to the families, and so it tells them that, hey, you have an upcoming appointment. This is the location and this is the date of your appointment. We did add a disclaimer at the end to contact the facility directly. When we first started, this we had a lot of families calling us saying I need to cancel my appointment, so we had to quickly change that, if you need to talk about the appointment specifics, contact the facility directly. Sorry.

Okay, and then as I mentioned in our text messages, we have our website that is linked in there, so we noticed that was really driving a lot of families to our website and even professionals. The bottom of our letters to primary care providers violence our website. These numbers -- providers to our website. We had over 4,000 individual views to our home page. Our two most visited pages are early hearing screening page, which is right after the initial screen, what are the next steps for these babies, and then our second most visited page was the CMV screening page.

We noticed we had a lot of material downloads during that time, so our top downloads were the CMV protocols and the hospital protocols. And then our "your baby hearing result at risk" brochure, so those specific children at risk.

Okay, we noticed in addition to automating our follow-up, we had to look at data accuracy and I have acy -- efficacy. We hired a technician in the fall of 2021 and they helped us develop a document system to monitor data accuracy and look at the provision of technical assistance being provided. Since July 2022, we've been able to provide 110 facilities with technical assistance. We identified 277 data entry errors that we were able to correct and fix that were entered by our stakeholders and we noted that over 1,301 professionals were viewing our recorded technical assistance trainings on our website.

Additionally, our EHDI information system has built-in systems in place to prevent incorrect or inaccurate data entry. So, what that means if they are putting in contact information, they have to put a phone number in. If they try to bypass that field, the system won't let them move forward and a pop-up will say, we need you to provide the phone number before you can move forward.

We also developed quarterly reports for stakeholders that they can self-generate. They can put the dates they want to look at and they can tell what their quarterly compliance rates were or the areas they can improve in their reporting process. And then, in addition to enhancing our system, we want to look at how are these enhancements affecting our follow-up rates.

We looked at some of the major impacts to our follow-up and we improved efficiency and timeliness that we're able to provide the follow-up in to these families. We're able to capture real-time conversations to use as quality emimprovement, to enhance the messaging that is given to families and we can maintain the continuity of follow-up, if staff is going on vacation, we can pick up and continue that follow-up throughout. I will pass it over to Parker to share some of the data we're able to identify.

>> Parker Brodsky: In 2021, Virginia had a 97.7% screening rate and we made 4,900 calls, sent 14,000 texts and mailed out 19,000 letters to primary care providers. This graph shows the numbers of days between initial and rescreen from December 2017 to December 2021. The goal here was to see the impact of initiation of texting in 2018 and how that would, hopefully, reduce our time to rescreen. You can see in that time period, our time to rescreen decreased by 27 days. We can't say for certain this was due to texting, but we plan to do a more thorough in depth analysis to see if this decrease can be attributed to the follow-up measures.

So, in this graph, you will see the number of follow-up activities for children with hearing loss versus the number of follow-up activities for children who were lost to follow-up. Children who were lost to follow-up received more texts, letters and calls in proportion to those diagnosed with hearing loss co which could be due to a longer follow-up timeframe with the timeframe up to 36 months of age. It causes us to do a deeper dive into why certain populations are being lost to follow-up despite the extensive follow-up measures from the EHDI team. That is another thing we plan top continue to look into.

This last data appointment shows the average age of diagnosis at hearing loss in days from 2018 to 2022. As many of us working in EHDI know, our goal is to diagnose all children before 3 months of age. In 2018, we were diagnosing children at just under 5 months and in 2022, which are numbers are not finalized yet, but our time to diagnosis decrease told just over two months. You can see 2021, which is our most recent year of finalized data, the number of days to diagnosis was two and a half months. There are two key developments that could be influencing the downward trend. You see two dashed lines on the screen. The first one in 2018 shows our implementation of texting. And then we think that could be a factor influencing that study downward trend in time to diagnosis that we have seen over the past five years.

The other one could be the initiation of our hearing targeted CMV screening program, which was in September of 2020. So, those are two things that could have influenced this, you know, steady decline, but we're definitely encouraged to see the decreases in the time to diagnosis, time to rescreen and all of that and again, we plan to continue looking more in depth to see the exact impact of the automated follow-up measures. That is it from us, but we're happy to take any questions you may have. I don't know if we want to pass this mic around or if you have one in the back. Thank you all.

>> Audience: This is just fantastic is all I want to say. Can I ask, is this an add-on system to your current data system? Like a phone system that you added on or was it developed inside your current system?

>> Daphne Miller: It is in our current system, so we have our internal IOM, information management team that we used to add on. But the texting is through twilio, so we worked with WIC. Sometimes we don't have a lot of funding, so we worked with our partner WIC and asked them if we could add on to their system, so they allowed us to add on and we just pay our bill, our portion of the bill. So, that has been helpful, because we didn't have to create anything. We just added on to theirs and it is minimal cost to do texting in comparison to mailing. We spent about $20,000 for mailing for one year and a text costs less than a penny a text.

>> Audience: So, you said twilio and you had developers that added it into your system?

>> Daphne Miller: Yes, we had developers.

>> Audience: Thank you.

>> Daphne Miller: You're welcome.

>> Audience: Did you have difficults where getting your state agency to approve the texting or was that already happening?

>> Daphne Miller: So, we just made a really good case. I think we came here in 2017 or whatever, and I saw another state, I think it was Georgia who was doing texting. I went back to my state and we figured out a way to get it done. We told them, we're not going to provide any sensitive information. We're not going to -- we said, you know, we put a PowerPoint together, I think and said, here is this is what we're going to tell families. this is what we're going to do and that is how we got it passed. We needed them to see what we're planning to do. It wasn't very difficult, because WIC was already texting so, it was happening with other programs and we wanted to do something similar.

>> Audience: I don't know if I miss this would because I came in late, what data management system do you use? It is homegrown?

>> Daphne Miller: It is homegrown.

>> Audience: Of course.

>> Daphne Miller: We have been asking if we can sell this system. We will have to look to see if we can do it one day.

>> Audience: You mentioned the cost of sending letters to your PCP. Are you mailing them?

>> Daphne Miller: Yes, we currently mail letters to PCPs.

>> Audience: In Minnesota, we use a fax system called Esker, we use a fax system.

>> Daphne Miller: Currently in our system, PCPs if they have access to our system, we're trying to give them all access to our system, right. The goal is they can go in the system and see all of the results. They can see the hearing screening results, the CMV results and see to letters in the system. We're trying to get them all in the system, so we don't have to mail the information out, but the goal is to have a reminder for them to go in the system. So, like, not necessarily will we create a link to send them, but we would say, hey, send them an e-mail and say you have three children pending that there is information on, that kind of thing. The parent is the one we want to have electronic letter more than the PCP if that makes sense.

>> Audience: Hi. What do you include in your quarterly reports for your stakeholders and how do you send those reports out?

>> Deepali Sanghani: So, in our quarterly reports, we have one for hospitals and audiologists and we recently developed a report for CMV. We include compliance rate, what are the days, the amount of days since screening and reporting. We give them a summary if it is like a three-month period and they have the ability to max like a year, I think. They can see how many children they screened, what were the result, and then also, see how many users they had and for audiologists, we try to give them a summary of how many diagnosed did you have in your facility? How many were lost to follow-up that were you were supposed to see but never returned? For the CMV, we're providing a report to show them how many baby were screened at the facility and what areas of improvement for screening. It's in the system. The question was, do we email it out to them? It is in the system, so they can self-generate it. They log in and there is a link and they put the dates and parameters they are looking for and it self-generates.

We also have pending lists for audiologists, so if the hospital says that they are going to this facility, then the baby gets put on that pending list for audiologists and they can find them easily and report the results for the screening. Okay, I think there is maybe one more question we could take.

>> One minute. Anyone else?

>> Thank you.