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EHDI – Florence

Follow-up to the Infinity

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>> Hello, my name is Antoinette Vaughn. Welcome to the Follow‑up to Infinity presentation. The objective of the presentation today is to share an overview of the Virginia Early Hearing Detection and Intervention follow‑up process on and tracking system. The online tracking system is the Virginia Infant Screening Infant Tracking System or what we refer to as VISITS. Early intervention providers and PCPs can gain access to visits to view a child's records and to enter hearing screenings and diagnostic data.

So... when vital records enters an electronic birth certificate the child appears on the birthing facility's pending list. These are some of the things captured on the pending list. The child's name, ID number, information like that. And if a child passes the hearing screening bilaterally... the results can quickly be submitted to Virginia EHDI, by checking the past paths box, excuse me... then selecting the date of screening and choosing the type of test performed. Once this is saved, the child will come off the birthing facility's pending list.

If, however... the child doesn't pass the initial newborn hearing screening, more information is required from the VISITS user. We'll need the name from the PCP responsible for the baby after discharge. The child's primary contact information, things of that nature.

We also have a section which is pretty helpful called special circumstances.

Now... this is where a user can provide Virginia EHDI with relevant information, additional things, such as if the child has been adopted or if they have other health issues that may not appear in other categories or sections of VISITS. Once they enter this data and save it, as you can see, the note is in the upper left‑hand corner, highlighted in yellow, and that flags us.

Once the above information has been entered, the VISITS user can discharge the baby. Discharge before screening. They need to answer yes or no to that. The date of discharge to home. If the child was not screened, then justification would be required.

Also... if you look down, a little bit further, risk indicators are captured on this page.

Next, this is where the user will enter the screening rights. OAE or automated ABR, bilateral results and name of the hearing screener. We have a new feature that was recently added in the fall of 2018, the audiology pending list.

So... by selecting the next appointment facility and the date of the follow‑up, they are, officially placing that child on to an audiology or hearing screeners pending list.

So... now, what we would do is look at this child as if he or she appears on the audiologist's pending list or as they appear.

So... as you can see, this child is now on the audiology facility's pending list. If, for some reason, the child no shows for the appointment, the user can click the drop down arrow and then select the reason the child didn't show. Whether they no‑showed, cancelled, whatever the case may be.

If the baby wasn't tested, the user can submit the results to Virginia EHDI by clicking on the child's name. The user will provide the date of test, the type of test performed, and the bilateral results.

And the user can either enter new‑risk indicators or whatever's there. Some of this may happen after discharge.

If a child is diagnosed with permanent hearing loss, an automatic early intervention referral is provided via VISITS. This refer is generated in 24 hours and early intervention will have that update. This is how EI users would get the referral information ‑‑ once they do that... they can easily report whether the child was enrolled or the family chose to decline these services, the reason for declining and the date of their decision.

A new feature also is gathering the IFSP or Individual Family Service Plan date, so... that's additional information and basically, this is how all of the different users that were mentioned earlier would utilize VISITS.

>> Antoinette did a great job explaining how users can use our system, we wanted to start off so you can get an idea of the information our system gathers and how it allows us to provide follow‑up.

So... once the users enter the information into VISITS, VISITS will generate a letter to the parents as well as the primary care provider.

The letter is going to provide them with the results of their initial hearing screen or rescreen and then the next steps that they need for follow‑up as well on the back of our letters ‑‑ we have a list of audiological facilities in our state where they can make an appointment if they haven't already done so.

And then we send a similar letter to the primary care provider, so that they can provide that information to their patients. We also make a phone call to the parents and during the call, we discuss, again, next steps for follow‑up so they can reach a diagnosis by three months of age and then... we also link them up with EHDI‑PALS or the back of our letter.

So... the text messages, it's an automatic text message that's generated in VISITS and so... as you can see, our VISITS system will show the wording of the text that was sent out and parents can reply to the text and will be able to see the wording of the text in our system when they reply. So... that we can follow‑up with them based on ‑‑ this is all from a testing site. So... you know, we just ‑‑ written some generic stuff. The information that you can see, our text doesn't have PHI, it's just a generic statement like "your child needs further follow‑up." It'll give a phone number to contact Virginia EHDI and link them to EHDI‑PALS so they can make an appointment.

And we have a detailed summary of the texting. We can filter it by the type of text that was sent out, if they need a rescreen ‑‑ it let's us know whether the text was delivered or not... that way, we can check and see, did this family get the text or not? And we can call them, if not, to further follow‑up.

This is a quick snapshot of the children that were born in Virginia, 2016 and 2017. The pie charts represent the number of children that we followed up on. The red is the percentage of children that passed with risk and each year, the blue is a percentage that failed their initial screen, and... the green is the percentage that missed their initial screen.

So... like I mentioned earlier, we send a letter to the parents as well as the PCPs, so... the PCP letter, they actually fax them back to us and they let us know where they were referred or... if they ‑‑ if the child had follow‑up, they'll send us the results in that fax.

So... as you can see ‑‑ the calls we talked about earlier ‑‑ we had a drastic jump in 2018 in the number of calls. That was because that was the one year ‑‑ the EHDI program was fully staffed. You can see the difference it makes in the number of people we have.

We also send e‑mails to stakeholders and to parents. The stakeholders would be to try to figure out if the child did follow‑up with them or where they were referred and to parents if they need resources. If they need permission to e‑mail them, we will e‑mail them as well.

We do provide referrals to bordering states if a child was in that state, but born in Virginia, we'll send them the results of their screening or rescreenings or diagnostic testing and send the letter we sent to parents so that state EHDI program can follow‑up with those families when they go back to their home state.

Like I mentioned, texting is new for us. We started in August of 2018, so we're doing a lot of PDSA on that, but a quick snapshot of how many texts were sent out during that time from August to January.

If a child is diagnosed with hearing loss ‑‑ if they have a transient or unknown hearing loss, then we'll follow‑up with them to determine if, you know... what the next steps were. Do they need to go see an ENT to get them to a diagnosis? And... then, if a child is diagnosed with permanent hearing loss, we send them a whole packet of resources and we'll also call the family to discuss referrals and additional resources that are needed.

So... our system as Antoinette mentioned, we do automatic referral to early intervention ‑‑ it's always 100% referral for early intervention, and we discuss referral to ENT, ophthalmology and genetics for the CDC guidelines and we also ‑‑ every child that's diagnosed with permanent hearing loss in our state has the option to talk with another parent, of a child with hearing loss.

So... if they choose to be referred, then we will refer them to our family to family support program for additional resources and support.

So... when we make that initial phone call, about three to four months after that, we do what we call an outcomes call. We're calling the family to see, did they actually go and enroll in early intervention or did they decline? And then the providers they were referred to ‑‑ we document whether they saw those providers or not.

So... just a quick snapshot and then with family to family, if they were referred, sometimes they, they don't make that connection with the parent and so... we're able to capture that as well.

We discussed communication options both in the referral and outcomes. We gather the data by the date of when the referral was made or the date of service for outcomes, so... we can't capture all the communication options yet, in our system, but we're working on that. If the child chooses hearing aids or cochlear implants, we put in the date they got the hearing aids or the date that the cochlear implants were ‑‑ the surgery was done...

>> I'm going to talk about the future enhancements of the system to support follow‑up. Although we have a robust system, we're not sure ‑‑ we want to ensure that our system is still friendly, obtains accurate data.

With that, in 2016, 2017, we realized we had gaps that needed to be addressed. One of those gaps were border babies. The others were the birthing center babies. We had over 297 children born in a birthing center that didn't receive initial hearing screening.

Then we had over thousands of children born in Virginia but residents of another state. And then, the number ‑‑ so... we know the number is highest in the DMV area, Maryland, D.C. and Virginia.

Moving forward, we came up with some strategies. One of the strategies we developed was to include enhancing our system to report, to allow reporting of out‑of‑state hospitals. Those children who are transferred to Children's National in D.C., they'd transfer to our system to enter in reports.

Also... we secondly, Washington, D.C., Jada's here, allowed us to go to site visits. We have Georgetown and children's national that we visit together and they were willing to say that they wanted access to our system to report many of the children in their state.

So... we just got the permission to get out‑of‑state reporting, so... they'll have access to enter their own audiological reporting forms.

And then, we moved forward, and this wouldn't have happened ‑‑ I'll say ‑‑ this wouldn't have happened without the support of Jada and Maryland, we also work with them, so... I'm so happy they're willing to allow us to come in their state and have facilities to report. I'm happy about that.

The other thing we wanted to address was the need of birthing centers. We didn't know what their need was. We decided to go out and meet with birthing centers. We realized they couldn't afford the equipment to test the children. The majority of them said, we're willing to report in a system ‑‑ we're willing to test children if we have access to do that.

So... right now, we're working to get at least 13 to 15 OAE, equipment to meet the needs of the 299 children we talked about earlier.

The other thing is a texting platform. We are doing some PDSAs around texting, looking at whether that is ‑‑ what day is the best day to text on, whether parents respond in the morning versus the evening.

If the texting wording is working, like, did this like the wording we sent them? We're going to work on it, see what the PDSA let's us do from this. Also, we're going to look at the platform ‑‑ the platform allows us to do more than just texting. It allows us to send videos, it allows us to put links in there ‑‑ where we can send videos, so... we're going to look at that over time and also, maybe, considering some things with using the shared plan of care... as someone way of texting families pieces of that. Because... we know that families are using their [indiscernible]. We're going to move forward with trying to figure out other ways we could use texting to benefit.

And another thing is, we'll start collect ing the VICA [phonetic] and adding a new module for the CMV, which has been legislated in Virginia now.

And we also want to send a reminder letter to families when they have children who have risks. We now send a reminder letter immediately after we find out there's a risk indicator, but we want to send one later down the road, about 12 months later to say there's a reminder, you need to go back for audiological diagnostic evaluation before your child is 24 months of age.

So... we're going to move forward with that. And those are a couple of our views ‑‑ a few of our enhancements, but not all of them.

And then... we have the shared plan of care. We've been working off this for awhile and our stakeholders are very excited, as we are, about this. We'll be putting this in our system. We can come up with more paper, but the true thing is ‑‑ we need something we can track. So... that ‑‑ we will give access to audiologists, early interventionists, family to family and... they will have access to the shared plan of care so they can all see what's happening with that child.

That's the next step moving forward this year.

The thing that's really helped us over the years is VISITS training videos. Our website has videos on it ‑‑ we cannot figure out how we wanted to do this at first ‑‑ we were spinning our wheels, going out for trainings at this hospital, this hospital and there's new staff all the time. The turnover was really high. So... what we decided to do was use GoToMeeting to record trainings. And we decided to make them short because we know that hospital staff are saying "I don't have an hour for this" or 30 minutes. We made videos that are like three to four minutes long on our system. You can say, how do I put adoption information in or how do I work the pending list? Easy things so you don't have to sit down for an hour to do a training. It was saving our time and their time.

So... it is on demand. So... whatever they feel is comfortable to watch the video, they can. So... that's a little about our system. We apologize because... we actually ‑‑ we're going to do a system live for you guys... but we found out they couldn't accommodate that, so... we had to do screen shots. We know it's a little bit difficult to see the screen shots, versus us moving through it. That's basically... Virginia's EHDI system ‑‑ thank you for coming. Do you have any questions?

>> So... the texting platform ‑‑ can you tell me more about that? Is that... like a stand alone? How is that integrated with your system? Is it available to others?

>> We use a company called TeleTask. I believe that's the name of the company. We wanted to do this alone, but found out that WIC was also text messaging. So... we combined with WIC and it allows our text messages to become a lot cheaper. They're very inexpensive that way because WIC sends so many text messages out, compared to us. When we got on the platform together, we designed it that TeleTask does most of the work.

>> Speaking of approval to do it, how do you get consent to do it?   
 >> Well... I thought it was going to be a lot more work than it was, we just sent up ‑‑ first we did presentations on it. We left this conference, when other states had done it and we said... listen, we're not sending PHI, we want to be generic ‑‑ so we got the messages approved, then we set them up and they just basically ‑‑ it went through our Office of Information Management and they approved it. There wasn't anything they were sending that was outside of the norm.

>> You didn't have to get special approval to text versus call from the patients themselves?   
 >> Nope, mm‑mmm. From the patients, we did, at first, send things to hospitals ‑‑ we wanted to get accurate information ‑‑ accurate phone numbers ‑‑ we did do like a ‑‑ a flyer and stuff, saying "get this person's phone number" and... actually permission, but... actually, the law says that we have ‑‑ we had to provide follow‑up. We know that follow‑up for us is now texting.

>> I also started texting about a year ago for follow‑up, but... what happens in your system in a family texts back?

>> So... I'll just go back quickly to that slide... but... it may be difficult to read, but... you can see like... the first one, and the bottom one is a reply, from a ‑‑ from a parent, so... it'll show us the actual words and then, like... their phone number... as well as you know... what time it was done, but... it'll show us exact words. So... we can see it, specifically, this is like the child's chart, so we can see it in there or we can go to the summary page and we can filter this status, and... this, right here, this is like the text that we sent out, but we can filter it back in and it'll show us all the text messages that we got in.

>> So... can you type back?

>> So... we can do it ‑‑ but we haven't done it yet. So... that's something that we will be doing.

>> Thank you.

>> All right... any other questions? Okay... thank you, all.   
[applause]

[Presentation concluded at 3:42 p.m. ET].

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