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Using Hospital EHDI Data to Impact Change

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>> All right. Hello, everyone. My name is Michele. I would like to introduce our second breakout session this afternoon. This is using hospital EHDI data to impact change for families. All right.

>> Okay. I got two extra minutes. So I'm very excited.

(Laughter)

>> I need it. Trust me. My name is Patricia Burke, I'm the Oklahoma EHDI coordinator. I'm also a member of the joint committee on infant hearing as well as a consultant. And I know you're really excited to hear about EHDI data. Who is excited for some EHDI data? All right. I know half of you are EHDI coordinators so, you know, I can see.

 Are there any data people in the house? Oh, good. Okay. That's awesome.

 Well, today's talk, we'll mostly discuss EHDI data, so it is geared more towards EHDI programs and staff.

 But before we is it start, I always want to say that never has there ever been a greater time in history to help children with hearing loss than right now. And the truth is, we all get to be a part of it. So whether you are in the EHDI program or a parent, if you have hearing loss yourself or you're deaf or hard‑of‑hearing, all of us have a place in this. And I think so often we don't think about data and individual children, how those things go together. So my hope is that we'll have time to talk through that today.

 I've already apologized to both interpreters. She's shaking her head. This is about an hour long presentation but I'm trying to get this in to 25 minutes. So there's going to be lots of stuff on the slides. It's on‑line. I won't read them but that way you'll have the staff in front of. You does that sound okay?

 And because I like to talk, my timer is officially on, if you see me go like this, it's because I'm stopping the time sorry it doesn't go ding, ding, ding the whole time.

 So part of this project was funded by, with some funding from HRSA as well as CDC. So there's different components that they helped with, so we wanted to say a special thank you to those entities for helping our program.

 So today we're going to go through some EHDI data, talking about how we can maximize that data and then really how that really does lead back to individual children. Because I know as we see those numbers, it can get really hard to think of those families. So Oklahoma was one of the first states in the nation, we're the first five, to have law for newborn hearing, but just like the rest of the nation, we realized that about 50% of children who had hearing loss had no risk factors.

 So you can see there in 2000, it actually became law to do if physiological screening as well as risk factor screening. And it also mandated that hospitals would screen and report all of their data. So we all know they did that, right? Everybody knows it's what they're really great at.

 Well, so, prior to our hospital reports, I actually was the follow‑up coordinator, and I would actually go to hospitals and I'd say, well, state law says you're supposed to screen. How many of you think you're screening all of your babies? And you know what, every time, they said, well, yeah, of course, why wouldn't we screen every baby? Then ill I would say oh, yeah, state law talks about reporting. How many of you report or what percentage you think you report your data? Every time says yes, of course we're reporting, at 100%. But how many of you EHDI programs in the room have said, that's not really the story. Yeah, right? They're all saying we're doing it, we're doing it. But we knew back at our office that children were not being screened every time. We also knew that we had to contact hospitals over and over for missing and conflicting information. So we had to think of a creative way to make sure that hospitals actually knew the correct information. So we created a quality assurance data coordinator position, and this is one of our biggest projects out of that process.

 So we actually did some quality improvement, to be honest, at the time, we just called it let's get ‑‑ make things better. We didn't know it was actually QI. We just wanted to improve the lives of babies, right? And so we actually partnered with three different hospitals, so we had three areas that we wanted to look at, and so each hospital took on one. Somebody did referring rights, one worked on not performance, and one worked on not reported. And so we actually were able to do to do several QI processes. One of those was this. We actually called one performance right.

 And what we found is that if a hospital had a 95% rate, they were like yes, and they were high‑fiving each other. And I was saying no, that's five% of your kids you're not missing. So we actually tried it, we realized if we changed the name, which I know is super awkward and you're like, why do they call it that, it's we found out they'd say, okay, this is the population of kids we still need to make sure we're screening, this is the population of kids that we haven't reported, and we actually found that they actually were more invested, just by changing the name.

 So these are, I mentioned the three areas there. Like I said, we got to go fast. But since we've launched, then we just had our five‑year anniversary of having our hospital reports, so you'll see the data shortly. But we've actually increased our correspondences at least three times. We actually doubled it within the first year and it is actually probably even higher than that.

 We actually truly built relationships with our hospital facilities. We were able to communicate, provide troubleshooting, coaching. We've actually done some individual hospital QI projects with them. We've seen that hospitals have taken ownership of their data. Because really, at the end of the day, nurses are touching babies and they don't think that data is all that important. Right? They're just trying to take care of that child. So somehow we have to come in, as EHDI, and convince them that it really is important.

 And then we also found that we improved in all three areas over the last five years, and, because of that, we got to increase our expectations for hospitals. Everybody hanging on?

 Okay. Let's see. All right. We're doing good. Okay. So this is we're where we're going to get behind because the next two slides to me I could talk for 25 minutes and if you want to later, I will. But these are my favorite slides of all. I actually, you know what do I call it, I geek out on this, I really love it. So when we started our reports, we started, we realized that referral rates are going to be different than screening rates, right? We 100% screen, 100% reported. However, some children are not going to pass newborn hearing screening. They're going to refer, correct? And so we know that with JCIH we expect our average is about 2 to 4%. We remember those hospitals that I said, how well are you screening your babies? Because I said, well, how well do you think, do you think you're over screening, do you think have you lots of refer rates? Oh, no, no, we think we're doing a great job.

 One of those hospitals had a 33% refer rate. So much so that the doctor called me at one point and he cussed me out and said, you're an idiot, newborn hearing screening doesn't work. I see about every third or fourth child. And I said, no, correction, you see, literally, you see 33%, one in three children in your hospital are coming to you. And so I was able to show him the data and say, guess what, we know nationally that newborn hearing screening works. We know in our state that newborn hearing screening works. But it doesn't work at your facility. And you know who they were able to take that data and actually do something with it. So we actually, originally started, this was actually in our CDC grant where we were able to make categories of who we wanted to approach to see, like, so we had no concerns, all the way to extremely high concerns. So we actually prioritized the high concerns at first. But what we realized just the presence of the data and actually awareness, it actually changed, so you can see where we got rid of a high concern category and then we just had a high concern of 10%. So now we have, then, since we've been going, we've been able to reduce in the last few years even another percent. So if you have like a 1 to 5% refer rate or 4.99, you have no concerns at this time because that's what we are typically see, right? We know that some populations are going to change depending on their location.

 We also created a low concern rate because one site said we promise, we pass every baby, we want to be your good children. And she said ‑‑ and I said, well, why are you calling today? Well, we've screened this child 13 times. But we're going to screen one more time before we send you the results. Because by golly I'm going to get that baby to pass. And I realized that our goals were not aligned. I'm trying to help identify children with hearing loss so they can go through the EHDI process. It's not about saying oh, can you screen every baby. You know, we don't want to see pass, pass, pass. So we realize that some of those sites who are had really low rates, which some people might think was good, was not so good after all.

 This is my favorite slide of the whole presentation. So when we looked at performance rate and reporting, so we kept those in the same category, right? So you could see our high concern, when we started out, we did ‑‑ oh, quick thing. We did two years of baseline data to create these charts. And then we categorized the hospitals into these areas. We actually had one hospital that forgot to either screen or report about 30% of their children. But yet, their staff actually thought they were screening 100%. They all thought the next nurse to them was doing the screening. But they didn't have systems and processes in place.

 So my favorite line of the whole presentation is right here in the middle. So we launched the two years of retrospective data on top, and within one year, we were able to change our expectation just through awareness. So in the baseline data, if you were 4% not reported, you, I was not even worried about you. You weren't even on my radar. You were my golden child. But within one year, if you actually forgot to ‑‑ let's say perform 4%, you were actually the worst of the worst. So that's how much the awareness actually changed for them. So we have now moved it down to less than 3%. So our average is over 99% of screening and now most of our hospitals at least have at least 97%.

 Okay. My allergies really started kicking in about ten minutes ago, so I apologize.

 So with our reports, one thing we realized is it takes time to make sure we get the data. Then sometimes that data is conflicting. Or it's missing. And we have to make requests. Of course we also know that some babies are going to be in the NICU for awhile. So we create our reports, it's one quarter post. So and so you can kind of see the timelines here. Of course we do celebrate our fifth anniversary, and then our quality assurance data coordinator took another position, and so for the first time ever, we're not going to actually meet our monthly cycle. But, you know, sometimes things happen in EHDI. And so we just continue to make sure. And what was really actually interesting about it is that we should have said ‑‑ we're hoping to have them at the end of January. We're probably going to actually send them next week once I get back to the office. What we found is that hospitals have become not dependent on it but they want that information. They actually said well, I've been looking in my e‑mail box because I want to see how we're doing, I want to see if we beat last quarter, I want to see if we've made gains. We want to know that we're helping babies but we don't have time to pull the data. But because you present it to us, we can actually work with our staff and make sure we're doing quality care in this area.

 Let's see. Well, maybe the slide is that. Okay. Let's see. So we're going to go through these next slides pretty fast, okay? This is where we kind of have to cut it down for a little bit. So for each report, we realized if we make a definition page and provide that to the providers, that was actually helpful.

 We also provide two types of reports. We have a quarterly report that just tells the last three months. And then we pull it together for an annual report. So you can see there's a little difference.

 And we're just going to really quickly go through, like I said, these slides are on‑line, so if it is fast, you know, we can talk through it more later. So for our quarterly report, we realized if we add a letter, because sometimes, just because the data is there, doesn't mean that the nurse managers and the hospital management, one, have time to review it; or two, that they understand what is being said. So we actually break it down, so we give them a quarterly percentage and we give the concern level that we saw earlier. What we found is it is a 50/50 camp. Half of them like to know the percentage. But really they want to know, am I in trouble is what they want to know. Or are we doing good? And so that is where that concern level comes. So we're able to provide them the percentage. Some have asked for numbers. Others have said, well, I'd really just like a picture. So we'd be able to provide that as well for them, so you can see each individual month there as well. And then we can take that, and we've encouraged them to look at it on a month to month and quarterly basis. And it basically has provided opportunity for us to have communications with our hospitals.

 Our annual report, this is my favorite part too, not only do we have the annual percentage, we have concern levels and, you ready for it? We rank the hospitals. And you know where we got that idea? Florida actually published it years ago, you published your data online, we were at a EHDI conference and we said, wow, they published the data on‑line, if we can help the hospitals see the comparison, and it has helped. So thank you, Florida. I've been following you guys for a long time.

 So how does that look, right? Refer rates, we would we be able to provide them, they have the data, which gets kind of boring if you're not a data person. And then of course we have the charts, we say, look for the increase, see look for the decrease, and then we're saying, here are the numbers to prove it so you can see exactly where to go. Look at it and compare it by quarters. One trend we found. You know what quarter is typically the worse? Somebody make a guess, anybody.

>> (Speaking away from microphone)

>> Why? Exactly. We found there is a spike in November and December. That they forget to screen babies, that refer rates are kind of not so good, and they may not report those results. So we're able to show them and we were able to show trend analysis to say, guess what, for the last five years, you've really stunk in quarter 4. So, guess what, if you want to work somewhere, we should work in quarter 4 together. So we also have provided them tips. I said this was taken from a presentation that we've actually been providing to the hospital for the last two years. So I won't go through all of them with you, but you've got the there as well.

 So our state average in 2017, which is the last year that has been a full year that's been reported by all states to CDC, we had a statewide average of 4.74%. So two‑thirds of our hospitals had no concerns at all when it came to refers. A far place from where we started. But you can see there that range is pretty big, right? So if you're a data person in the room, it's like almost 0% to 13%. And what is odd is only 3 hospitals actually had over 10%. And you know what caused it? Equipment problems, right. I was just in a meeting she said this they had a child who was diagnosed at two years of life because the hospital was down for two weeks and her baby was born during that two‑week period. So really, each one of these children matter. And you know, just having a little bit of equipment down for just a little bit can really impact a family's life forever.

 So not performed rates, we dot same thing. So, you know, we look for peaks and increases, we pull the data, we say, what happened during that time

 In another time we find that's pretty interesting that there's a spike is typically May, a little bit of summer, but we've realized after talking to hospitals, it is when nurses graduate from school, and so they're going in to, they're adding a lot of nurses, so May and June is about the time. So we'll go through this one quick. We compare the quarters. And then of course we provide them some information how they follow‑up. Is it their systems in process, is it their equipment, maybe it's a supply issue, maybe it's an education issue I share the reports with each hospital.

 My favorite hospital training of all‑time, it's okay, I'm going to tell you a little secret, this is a little TMI, before every presentation, I go to the bathroom. So if you're in the bathroom a minute a, go I was in there with you. So every time I go to a hospital, I say, can I go to the nurse's bathroom? And so I go there, and I'm like really, I've got about ten minutes. Have you ever been to a nurse's bathroom? There is so much information. I'm like, I did not know that was the flu right now. Oh, I had no idea I needed to do that. Right? So the nurse's bathroom is full of stuff. So we actually asked them when, you get a report, will you make it a pot pee publication? Maybe a little pot pee public. Will you hang our reports in your bathroom? You know what, it made a difference. And so I walked in to one bathroom and the report was sitting there, like, on the mirror. And it said, the state is coming, you must come to this presentation, we are the worst.

(Laughter)

>> And it said, let's change that. And I was like, wow, isn't that funny that something as simple as getting these reports and asking them to put it in the toilet room, that it really made a difference. Oh, my god, ten minutes just so you know.

 Okay. So here's kind of what our list looks like. This will make a difference in a minute when you see the slide. But this year we a 27‑way tie where the hospitals screened every baby out the door. And it's the competition. And you can see quite a few hospitals missed it literally by one or two babies. So kind of not reporting ‑‑ not performed an not reported, this is your rule of thumb, so not performed is going to be the babies no longer there, they were not screened, so really, they don't have results.

 Not reported is more of the lost of documentation at the hospital level, so the baby was screened but they forgot to send the results to us. At the we also got missing, we didn't get it, core conflicting, the baby passed both the left and the right year, right? So we have provided training on that. We have a algorithm in our system. If you have questions through this, we can talk later.

 This is our workflow. We send results to hospitals for newborn nursery at one week. And then we send to the NICU at 45 days, although we're doing a QI project right now, we're seeing a NICU list of all children in the NICU so we can compare before we ask them so we can see if we want the ability to change that deadline based on when babies are in the NICU.

 So there's a quick QI, that's a buzzword in EHDI in the last few years. Simple QIs, one of them was what if we add you need to respond by date. We say deadline, you have one week, I send it to you on Thursday, I expect it back by Wednesday, because we are working together as a partnership. And so that has actually drastically helped hospitals responding, where before we were calling them over and over and over and asking them to send the results they were already supposed to send.

 So this is what included, we realized if we generated a template e‑mail, so it looks the same every time, because they're not going to read most of it anyways, if it is template, then they can know what to go look for. So we've trained them, this is what the e‑mail is going to look like, this is the stuff you need to look for and this is how you can respond back to us the quickest.

 So we won't go through those, same song and dance, we can compare by quarter, and then we've also provided results.

 Okay. So this is our not reported section. So you can see 63% had no concern. And as compared to the previous year and you can see it kind of jumped up. So we did QI projects in the previous year and we saw and made a difference, things like, hey, work with your laboratory that has the blood spot filter paper because you take the blood spot at 24 hours but it has to dry and it doesn't leave your building until 48 hours, so if you get it on that blood spot, you're going to have a better chance of getting it to us and you're not going have to do more work for your staff.

 Something that motivates hospital leadership is this reduces staff if you do, this your staff is over working here and instead you can spend more time doing patient care.

 So here is kind of that run through, we kind of went through those three different reports. But this is what it looks like over a five‑year period. You can see, for instance, our refer rates. You could see there was a spike between 2014 and 2015. You know what that was? Aging equipment. You know what we did with that data? We showed it to our agency, and they've given us $200,000 a years for extra equipment. Because we provide equipment to the hospital facilities if they don't have a vendor. So we were able to turn it around and show our leadership that we needed that.

 Remember I said 27‑way tie. When we started, only 12 hospitals actually said ‑‑ they did what they actually said, that they actually screened every baby so that not perform rate. And then you could see that not reported, my favorite part there is you can see at one point was over 2,000 children we had to ask for missing and conflicting information. And we've been able to cut that more than in half, from our original spot about 1,600 to about 800 there at the end.

 As we always say, it's the race to the bottom but not like it is in business, in a good way. So you want it to be closer to the bottom. We've been able to take this and show a trend. This is what I do not want to see. You can see this hospital was ranked No. 1 when it came to refers but recently they were ranked at 47. We can go back and look at the data, everything I do is color coded, so you can go back to the color chart and we can go look and pinpoint what was the problem.

 Here's examples, we've been able to do with vendors, been able to combine data from hospitals. They like to compare amongst themselves even, so be able to show them this is the trend. The first one on top, going down, getting better and better, right, the race to the bottom. The other one on the bottom, you can see some are going up and then you can see some are spiking and not consistent.

 One other thing we did was we actually right now we're just getting in to individual hospitals, so only hospital A knows that they're number five. Okay. It says we have five minutes. But we are hoping to eventually, we've been trying to work on it for years to get them transparent, I have to go through a o lot of loops through legal aspects. But since our agency wouldn't let us put it on‑line, so, to date, which is our hope plan for next year, we've been able to do webinars to provide for hospitals. And we have come out and just said, these are your star winners, these are the ones who are doing well. And something just as simple as giving credit to those who are working hard and doing well, these hospitals here, ten hospitals, had no concerns in all areas. One, we provide some mentorship from other hospitals, we take their information and ask them how they've had success and then we turn around and give it to other hospitals because they receive it better from when it comes from a hospital than just from us.

 So we also encourage weekly, quarterly and annual reviews along the way, right? But we also remind everybody that it is about family. So this is my personal family. And the truth is, this is why we do, it right? Its no the about just a number on a page and to see, did it spike data, did it spike ‑‑ did it go up or did it go down? It's about really impacting every single family, right? We know that they have ‑‑ that's just the start of it. So this is how it has impacted our families over the last several years. Of course, I kind of laughed when I looked at your presentation and saw the number of babies in Florida. So what you do in five years, Florida sees in a year.

 Somehow I guess people aren't running to Oklahoma, with the ice and the tornadoes. But it is a nice place to live if you'd like to go. Or at least visit. Just visit.

 So over the last five years, we've been able to help a quarter of a million babies at 50 birthing hospitals. We've been able to provide troubleshooting and resources. We've kind of mentioned identifying top reporters, but once again, we know that it is all an impact, right, so how does it really help families? What we have to know is when we screen prior to discharge and get a good quality screen, that actually helps with the one actually helps the three, right? Because we can have more timely diagnostics.

 High refer rates means the audiologist office is really business. But if you refer 33 percent of your babies, that audiologist schedule is out months. But if you have good quality refer rates, quality screens and quality refer rates, that means families can get into the audiologist more timely. That way families don't have to stress and worry, does their child have hearing loss or not have hearing loss, or how should I proceed at this moment? We actually know that reporting actually helps us, it helps us to be able to talk and communicate with parents, provide case management, work with the parent, work with the PCP. And, of course, once we get to the three, that helps the six. And then that's going to help with early intervention placement, it's going to help have communication options, and it is really going to maximize on developmental synchrony, right, where those children are developing at the same right as children that are hearing.

 So this is just a quick thing, I've got two minutes. So here is a rundown of what it could look like. Lower not performed and refer rates means, guess what, EHDI, we can track fewer kids but we can track the ones that count, that really need the follow‑up, right? We don't have to worry about all of the other things, if we have good, let's say, low refer rates, we can spend more time with them, right, so the next one says EHDI staff can talk to families, that reduces the number of children going to audiologists, save appointments, they think we can make more training with audiology, and it gives us more time for newborn partnerships with parent to parent support, with deaf mentors. So it really can provide a ripple effect.

 So I know that with our newborn guidance, a lot has been on 3 and 6 in the last few years. But I just hope that what we remember is that we do have to start at the beginning too. My hope is that we don't allow the foundation of where it starts at the top to go away. But once we do put that energy towards the hospital, we can, then, in the end, help more families. And what seems like a number, are can help impact a life. So if you have questions, feel free to let me know. And thanks for sitting through that. I know you're tired.

 So okay.

(Applause)

>> Anybody too tired from listening to the speed? Oh, do, we have time? Question?

>> I do have tired eyes. I was focussed on the slide. But I just want to take a picture of this.

>> Oh, sure.

>> Yes.

>> (Speaking away from microphone)

>> So the question is, how do we get the three hospitals to do QI with us? We didn't call it QI because we didn't know. We didn't know that term. And really, we actually identified the sites who weren't doing so well and we said, hey, we're about to start hospital reports, do you want to get on it now or do you want to get on it later? Because when you tell somebody you're 50 of 50 in an area, they get pretty embarrassed. So we didn't shame them. So we started with hospitals that were having a hard time. And hospitals were invested and thought they were doing better than they were and who said I just want to do that. So all three of the hospitals, one was doing bad, one just wanted to do better, so, you know, it would vary between hospitals. And it was QI because it was small systems of change, right, we did, planned the study act and then we replicated it. So yeah.

>> (Speaking away from microphone)

>> I don't know if you heard that. So she said one example of why not using technical terms sometimes, on the time we were just unknowledgeable, but we'll go with that. We were not use being technical terms to make sure everybody was on board. Good call. Yeah.

>> (Speaking away from microphone)

>> And with our transparent reports that should be coming out by hopefully next year, we said, you know we're about to publish these on‑line and everybody is going to know your ranking, and some of the hospitals we offered QI to before that said no now said maybe we'd like to partner with you now. So kind of encouragement. Yes.

>> (Speaking away from microphone)

>> Good call. I wanted to send it to the CEO and COO, but what we decided to do is we wanted to enhance partnerships so we sent it to the hospital nursery.

(Laughter)

>> Well, I said let's send it to the CEO, my boss said no, don't forget this is about partnerships. So we start with the nursery leadership and we tell them, as many people as you want can be on them. So one hospital that was really bad, they put all of their physicians in the NICU nursery, they actually are on the list, but usually it goes to the nurse manager and assistant nurse manager.

 Now, if they don't follow‑up well and they don't make change and they're refusing to change the reports, then move up to their QA or their risk management. And we have gone all the way to a CEO. And I'll tell you, it moved fast once it got there. Kind of scares you when you're 50 of 50. I've been told, you're okay, now, cut it out. Cut it out. Okay. You got to do the cut it out. Do you remember that? Nobody? Nobody? It's an 80's reference. Do you remember that. It was Dave Coullier. Cut it out.