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2018 EARLY HEARING DETECTION &

INTERVENTION MEETING

DENVER, COLORADO

TUESDAY, MARCH 20, 2018

AGATE A‑C

REDUCING LOSS TO FOLLOW‑UP DUE TO PLANNING AND TIMING

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>>: Good morning. Alexis is passing around some chocolate. We figured everybody could use a little bit of sugar to start the day here. I realize it's a couple of minutes before the hour, but if anybody needs to move or communicate to access, we give you the opportunity now to do that. We ask folks to please come in and fill in from the front in some of these front seats. Don't be afraid because you know how we all are. We come and sit in the back and ... all right.

So just kind of before we get started, how many parents do we have in the room? All right let's give them a round of applause because without the parents in the room obviously all of our work wouldn't be as full and beneficial to everyone. So how many EHDI coordinators do we have in the room?

All right. Manufacturers, contractors? Okay.

All right. Any other groups that I didn't find? Physicians? How many physicians? Nurse practitioners audiologists, medical personnel? I know audiologists wear more than one hat in that arena.

So we've got an incredibly diverse group so hopefully we'll speak to a few things. We only have 25 minutes today so I will give you a high level overview of some of the things we're done in Illinois. Are we okay to start here?

It looks like it's 11 so I will introduce myself. I'm Ginger Mullin I'm an audiologist by training. I spent 7 years as a pediatric audiologist and when the call came for me to be able to be a EHDI coordinator in Illinois, I took it and haven't looked back. That is my career and my passion and I love what I do. Illinois is now the six largest state in the nation. Weep slipped behind Pennsylvania because our birthrate is declining.

I also have Alexis Scherba. We are fortunate enough that even though we have five full‑time staff members in the I mean, EHDI program we have graduate public service interns that typically are masters of public administration or masters of public health and then join us for 20 hours a week during the school year.

>>: And 40 hours during the summer. So a lot of the innovative work and quality improvement work we do is because it goes under their category of special projects.

Come on in. No come on in. It's all good!

So Alexis will be here to help remind me of the things we do and also answer any questions that there might be.

These are the four things we were going to talk about today. Referring to local health departments, doing a data integration piece with Medicaid, implementing web based reporting and implementing hospital reporting.

Well, like I said, I've been in EHDI since 2005 but I used to work over at the division of specialized care which was the children with special health care needs program. In 2014, I came over to the Department of Public Health and how many people have started in a new job and within the first week you get a huge stack of here's your projects? Anybody have that? Yeah! Some of you are even crying about it but it's okay.

So that's definitely what I had when I showed up at public health even though I had worked on the other side. And you can see around 2014 we had the highest or almost highest birthrate in the nation. We were at 81 percent, and as of last week we were down to 35 percent for 2016. So we've had a significant reduction and we just wanted to tell you a few things as to how we got to that point.

Now, any of activities we talk about today, this isn't I thought I was going to write this into the grant and color code it and put it in a binder. No, it was all hey, Ginger, guess what, you going to do this next week.

So some of the things that were forced upon us to do but we ended up having great results with them.

At the time that we were doing all these projects or I switched agencies, we also had a change in our legislation. I just want to highlight a couple of those things. For one, we had to change from the word birthing facilities to medical care facilities so it would encompass all the free standing birthing centers in our state so they would fall under our legislation.

Another part of our legislation talks about reports to the department and we spelled out everybody and their dog. So that is in there. And then who can share with us. Again we got Fido in that list too.

What I will tell you is please don't go out to Illinois legislation and copy and paste to your State because what we submitted and what actually got approved were two different things because there were some lobbyist that got not that I'm aware finger on the legislation. So if you read it, it reads kind of interesting.

Because we've opened up the doors for reporting, that has also helped us with some of the projects that we're doing in supporting us and get knows MOUs or even just business agreements in place.

We do say that you only have to provide documentation for the services that you provide, but it does mean the ENT does have to tell us what they did and the doctor has to tell us what they did. It's not up to the audiologist to tell us what the ENT does.

So and, of course, we took this directly from Kansas. So those are the changes in legislation.

>>: Here is my little card too. We weren't able to do those run charts and decide what worked and what didn't work. We just were told you have to implement them and there's no opportunity to abandon the activity. So we're gonna start with web based data reporting. That was one that all of our hospitals were supposed to report within seven days. We had to do flat file transfers by e‑mail that took one full FTE to upload into our system. How many states in here are on web based? Anybody not on web based yet? If you haven't moved to web based I can tell you that's a huge piece. We were able to go through 118 medical care facilities, seven EHDI staff, get them up and running on the web based program, so that everybody could see what everybody else was doing. We thought that this was long hanging fruit. The cartoon here shows you that low‑hanging fruit isn't always the sweetest. We had some troubles along with it.

You would think everybody is seeing what everybody else saw would be great except for then you get people questioning what you put in your data system, how you put it in your data system so instead of having those five FTEs in your EHDI department you have over 200 people criticizing your data system. So for those who haven't gone web based, it is a blessing and a curse. The things that have been positive for us though is we have standard templates of how things should be entered into our data system for everybody to see. As well as we have the accountability that goes to the hospitals to enter all of the information. Before they would say oh, I sent you that file and we wouldn't know if that file got sent and just not uploaded yet.

Also the accessibility, that was a challenge because a facility administrator can assign users and sometimes they assign one user and they let three people use that password so we're instantly policing that piece of it.

Security and HIPAA compliance. We ended up archiving 2 million records in our data system so we could meet security so that the hospitals can't even access those records. We didn't think of these because we didn't have time to plan it out ahead. We had to go with it and get it done.

>>: Unfortunately our facility wasn't ready for web based so we crashed it couple of times. But would I still go back and do it all again, I would. I think Andrea who is one of our support folks, she can tell you a word about it.

I know Stephanie has the same system and it's a lot faster.

The hospitals are able to self‑monitor. There's accountability. We do report card now so if our data doesn't match their data, they can go right in and real time see why that is.

Also the documentation for outpatient testing is much better than it ever has been in the past. We've done PDFAs. After training, we found that we had a 70 percent increase in documentation since we've been web based for those outpatient appointments.

So with that, with our ‑‑ any questions about web based? I think most of you have done that but that's part of our success.

Our next part was implementing hospital reporting audits. So back in the day, these were extremely painful and could take hours. Anybody that was in our hospitals wasn't real fond of that but that was long hanging fruited for us because we had folks reporting more timely than ever. We were table to assign one full‑time staff member that does phone calls with all the birthing facilities and does one‑on‑one follow‑up. So we changed that from hospital audits to education opportunities. Our staff member calls and helps indicate the hearing screening liaison on proper use of the data system and documentation in the data system and that's made a world of difference for us because the staff turns over so quickly in the birthing facilities.

So what we did do though also with our audits is monitor how often the people are reporting data. That seems super simple but we never did it before. So we did our PDSA and we have run measures to do this. But at first we sent e‑mail reminder when they were greater than seven case from reporting. Then you can see the next big change. We sent phone calls to the liaison saying hey what's going on. Most often people were off on medical leave or it was a holiday. Then we implemented report calls and calls to the nurse managers and then you saw the shift of reporting there, and then finely we had the opportunity and the timing came up that we would present to the perinatal network and they asked us to please give them a call when reporting was an issue so they could intervene.

Do people understand what perinatal networks are? We have ten perinatal networks in Illinois. There's a manager that oversees those. So if something is going wrong in the hospital or there's a compliance issue, we're able to contact the perinatal administrator to gets involved on both parties behalf and helps arbitrate between the two and get the problems resolved and then those administrators report back to the Department of Public Health for the department's section that does the accreditation for the hospitals. So we actually have teeth in that regard. As you guys know we don't have teeth very often so ... any questions on that one.

>>: [away from mic]

The question was will we upload the presentation letter to the EHDI website. I can. Also we're passing around a little white baggy that has our cards in it, and if you want me to e‑mail you anything else, when we get to our HFS Medicaid, there are supplemental documents I won't be uploading to the EHDI website, but I'm happy to send to you offline. But yes, I can upload those.

So what we found in that reporting every seven days is kind of what we all experience at times if the right person isn't there, nothing gets done, right.

>>: So despite our efforts where we saw changes in data, we have seen now for two years, Fourth of July, Christmas and winter holiday and Thanksgiving, we always see delays in reporting. We have because it's been such a great success of uploading, we have asked that folks upload every three to four days and we have 62 percent compliance with that. So part of that is ‑‑ I'm going to take a sidebar here. Part of that is gone to our contract companies and said we want to hold quarterly calls with you. And let them ask us questions and we can ask them questions. And I think once we explain some of our issues on the state side, we've had better compliance or even the things that aren't mandatory but the things we're asking for, they're doing. So I think that leads into the 62 percent compliance with reporting every three to four days.

>>: So in the monthly education and audits we now have two EHDI staff members that it's not their full‑time job but a big portion of their job is to reach out to the 118 facilities. Originally we intended this auditing process to completely go away when we integrated with vital records. Our process of integrating with vital records has turned a little bit of a Gilligan's Island. Instead of a three hour tour we're at about a three‑year tour. It's taking much longer than what we thought. We have decided we won't discontinue this auditing process because it is more of an education process as well as on a later slide you'll see we give a lot of intel by doing these calls. We find out who just got fired. Who's leaving their jobs. Sometimes we find out somebody is leaving a job before they even tell their boss. We find out when contact companies come and go. We find out when equipment is down. So if you don't have those monthly calls even if it's just 15 minutes with your birthing hospitals, we do have data run measures to show you it's extremely beneficial and it's worth the tile and with ‑‑ worth the time and with only a staff of five in our state, obviously staffing is critical, but it's worth it.

So the other thing that we have done is we've looked at ‑‑ you can see if we look at quarter 1, versus quarter 4, and we start talking loss to follow up and we show them if they're not entering the data or the follow‑up information, they end up sticking at that high loss to follow up rate. It's because they put the follow‑up information that the child eventually resolves. The other piece this data shows is it typically takes a couple of quarters, six to nine months, before we can ever close a child and I don't think our hospitals understood that previously; that they thought oh, we just screen them and we're finished, but when we show them the data it actually makes sense to them.

I think we've talked a little bit about this.

So obviously time is a challenge. It is a manual process. We've talked about these. Okay.

So our next one is ‑‑ this was another one that I actually had a staff member at the time that the first day I came in, they said, you know, we're supposed to be referring to local health departments. My answer wanted to be well why haven't you been? (laughter). But so we had to implement it because we had somebody that was very passionate about making sure that was done because that was in our administrative rules. So again did we get to plan it out quickly? No. We were forced to go very quickly at implementing something that had been in the administrative rules for a decade but that's okay. We made lemonade out of lemons.

So what we ended up doing is we had to work with our high tech vendor to make sure on every letter we could transpose the zip code into what actual county it was. When we first started we looked up 62, 65 letters every single month and looked up the zip code and wrote the county. Our vendor at least helped us out with that. So then we started sending and faxing those letters to the local health department.

Maybe I should back up and tell you with the referrals to local health department what happens in the State of Illinois, the hospital tells us the baby doesn't pass. We send a letter to the parents and physician. At 30 days we send a letter again to the parent and physician. A lot of you are going that's a lot of people. It is but this is the way it was set up. At 60 days if a child has resolved we send a letter to the parent, the physician and the local health department asking for help for care coordination or documentation.

We follow the exact same model, genetic metabolic uses. And the local health departments were resistant at first. When we explained they are like oh, we'll treat it the same way. So at first in the first box you'll see that we just sent referrals. It was a hey we can't plan it. We have to implement it. And we're going to hurry up and go. And we were able to resolve anywhere from 20 to 30 percent of our kids that we sent. Well, that's not too bad really.

We were kind of happy with that. But we knew we could take it further so this is where we did do the planning and we did do our PDSA and we sent the next month with all the kids who hasn't passed a flyer that showed the newborn hearing screening training curriculum. You can get two free continuing education hours for watching this curriculum. And it will help you learn a little bit about the EHDI program and what happens and why we're asking you for follow‑up. Because we couldn't get to 100 health departments across the State of Illinois, and you see we significantly jumped. That's because there was a little bit more work involved.

The next time we started a local health department work group and we have them working on developing recommendations for follow‑up we're not going to call it a protocol because in Illinois a lot of the health departments have changed what they're doing because of the funding. A lot of programs have closed. They don't offer those services that we used to. So we have some challenges there.

I cannot explain that dip in month No. 10. We have tried to isolate what that was and why we had so few follow‑ups. We don't know but you can see long term we continue to have somewhere between 40 and 50 percent of all the kids that we send are resolved. Resolved means we either found out sadly the baby expired, the baby moved out of the state, the baby has an appointment or the local health department actually sent the results to us. So that's what we call resolved. And then last we did include the local health departments in our learning communities and all you coordinators know what those are.

As of yesterday the brand new version launched. If you have any questions about that, happy to talk offline and, of course, the mother of that project is Randy Winston. So we have over, I think, 800 participants in the last year that have taken that.

The or things that have happened out of working with the local health departments is the local health departments know the community resources so that's the way we've been able to tap into transportation issues which we all know is a big problem. For me to give a voucher to every child that needs to go for follow‑up I wouldn't have money to do anything else in our state but the community resources, the chunk or loins clubs will help parents. They do have some vouchers for buses or taxis or I've heard they're using Uber.

It's been helpful with the local health departments because they're getting to the audiology.

We did another PDSA and we modified our form so we're able to know was face‑to‑face contact made, was phone contact made, were letters sent and it helps us complete or CDC survey.

So that was benefits for us and it wasn't work that we had to do at the state level.

Then finely what that has led to is local health departments have offered to do screening. They call it drive by. I'm not sure why. So when they go to see a family who is there, they will take the equipment. I was told five minutes so I will jump through and talk to you what we're most proud of and that's data integration with Medicaid. So to give you the short version, what happens every month ‑‑ I'm sorry every week in Illinois is our EHDI system uploads to an electronic warehouse. Because of a clocks that started before ‑‑ collaboration that started before I got there, we were able to agree that we were going to match all the kid that were unresolved and what is sent back from the electronic data warehouse electrically to the Ed EHDI is the parents address and the primary care physician. So that automatically imports into our data system, and the whole process ‑‑ the process is actually quite easy. It's having IT time. I think that's the biggest challenge. A dedicated IT staff that's willing to do the data matching for you. Our vendor, you probably know who that is. If you have the same vendor as we do. They've done this several times so it's not a problem. It was an easy data match for them.

It was a data match for them and then we're able to review all the records based on changed state, update physicians, the physicians will update automatically if there's a match in our system. Then we're able to generate letters and make phone calls to those doctors. So this is probably what has been the most beneficial to us. The downside, this shows you every week we send about three thousand data files to the data warehouse, and what we get back is seen on this graph. So how many files are unresolved and returned to the EHDI program. So in week one, 293 cases were updated. The next week 225. If you look at where there was 182, 115, and 62. Those are weeks I was out of the office. Quite honestly I couldn't figure out why it was so low and I had IT calling me because I get an e‑mail every week saying the files have been upload and downloaded. Each way it tells me it has been completed. It only sends the files that have been touched in the last seven days. So if you don't have somebody in the office touching files it won't resend them to gather the information. Does that make sense. So you can see that probably between 62 we can 115, are the new files uploaded from the hospitals that need to be data matched. The others are when folks are touching the files and reviewing the files. Then they get recent to Medicaid.

So I'm actually going to stop there and ask if there's any questions. I know that's a super high overview but we did pass around a little white bag that has our card in it. We're happy to talk to you further about it. I encourage everybody if a project is dropped in your lap and you have to do it go ahead and start but then figure out how to use quality improvement to continue that project on. And I think all of us are sometimes like I gotta get it done by next Thursday. Well, you get it done by next Thursday but then look at how you can improve beyond where you're at.

Any questions.

>>: [away from the mic]

>>: So Stephanie's question when do we involve the local health department. 60 days.

>>: [away from mic]

>>: What's the primary purpose of the local health department. We ask them to help us locate documentation of testing that was done or coordinate for the child to get the services, outpatient screening or audiological. In Cook County we have a project where they're go to take screening out into the house into the home to get the screening done. I'm an audiologist by training and I have that lump in my throat about it but at this point it's a way for us to try to follow up on those kids.

>>: [away from mic]

>>: The question is are we providing funding to the local health departments. No, it's part of their agreement of what they have to do with genetic, metabolic and we were able to slide in under them so there's no funding exchange. This is Illinois, honey (laughter).

>>: [away from mic]

>>: So you're on the ‑‑ Arizona is on the same data system we are and the question is what do we do when they don't follow up for that appointment. The local health departments have taken it upon themselves to follow up with the families. We did not ask them to do that, but they get so invested in the process that they go to see if they followed up with the appointment. The audiologist we've done education for them. In Illinois we actually generate a broken appointment letter to notify the physician that the family never showed and to send the family a letter saying call us so we can help you to keep that appointment. We document that.

One more. Yes, ma'am.

>>: [away from mic]

>>: Sure. She is talking about the accountability for every infant. Son we're closer than we ever have been but until we truly link and do a data exchange file transfer, we're not going to do at 1 a hundred percent. What we do in the interim is my wonderful graduate intern does an extract from vital records and extract from EHDI IS and does a data comparison. And we send that information to the hospital prior to our education and audit appointment. So it sounds like a very long process, but it actually is not. These ladies are able to ‑‑ I think our Northwestern audit which is 11 or 12,000 births a year maybe takes you guys, what, 20, 30 minutes.

>>: [away from mic]

>>: Right. So I mean 12,000 births is, you know, more than North Dakota. I love North Dakota. We have a form there. But for the other hospitals, you're talking about 10, 10 minutes. These ladies have gotten that process down and they're willing to share that with you. We're going to do some video training on how we do that for our own staff and we're happy to share that. But 10, 15 minutes of that data match and we send that ahead of time to the hospital to know what's missing. So I need to be respectful of the second presenter so I thank you very much and have a great day.

[Applause]