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EHDI 2019

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FLORIDA’S EARLY HEARING DETECTION

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>> Hello, everyone. If I could have your attention. My name is Michele. And I'd like to introduce Florida's Early Hearing Detection and Intervention program, descriptive and spatial analysis of 2015 and 2016 data. You have your evaluations, or you can do it on your phone, so thank you.

>> Thank you. Well, good afternoon, everyone. I am Jessica Meyer. I am the EHDI coordinator for the state of Florida. I'm fairly newborn in this role as far as EHDI coordinators go. This is my second year. So what we have done with this program is our health data analyst, Nikema Peterson, did some foundational research based on our 2015 and 2016 data so that we can kind of get a good picture of where we are as a program and think about ways we can improve going forward. So I'm going to give a brief overview of how the EHDI program and EHDI system works in Florida, and then Nikema is going to go into the research she's been working on this year on our data.

So as most of you probably already know, hearing loss is the most common birth defect in the United States. Between one and three babies out of a thousand are born with permanent hearing loss each year. In Florida, an average of 9,000 babies don't pass their hearing screenings. And then out of those 9,000, approximately 300 babies are diagnosed with a permanent hearing loss.

So what is EHDI? Early Hearing Detection and Intervention, or EHDI, is a national program which was authorized by Congress in 2000. The goal this program is enhance language, communication, cognitive, and social skill development that is needed to be successful in school and other aspects of life. Our EHDI program includes the screenings which is the initial test of infants for hearing loss, audiological diagnostic evaluation to confirm hearing loss, or normal hearing, and early intervention.

So as we stated before, hearing loss can affect a child's ability to develop speech, language, and social skills. The earlier intervention is provided, the better chance a child has at reaching their full potential. The Joint Committee on Infant Hearing, the JCIH, recommends that hearing screenings be completed by one month of age, that hearing loss is diagnosed by three months of age, and that early intervention enrollment occurs by six months of age.

The newborn hearing screening follow‑up program attempts to obtain rescreenings for babies and children up to three years of age who didn't pass their hearing screenings. The programs objective is to encourage early diagnosis, to allow for early intervention. So the process in Florida obviously is a baby is important their hearing screening is completed, usually in the hospital setting, and then if they don't pass that screening, we are a two‑screen state, so that second screening is completed either before discharge or in a outpatient setting.

Once the EHDI program or the newborn screening program is notified that a child referred on their hearing screening, we're completing outreach and follow‑up, so sending letters, and phone calls and faxes to pediatricians and families trying to encourage those families to pursue diagnostic testing to confirm a hearing diagnosis. And then once that occurs, they would either receive a diagnosis of normal hearing or some sort of hearing loss or impairment.

Once that diagnosis of hearing loss is reported to our staff, results are entered into our system. We assemble a packet of educational materials that are specific to hearing loss, and we send it to parents or caregivers, and then we also make a referral to the local early steps which is our Part C early intervention program in Florida. We send that through fax or as well as through our secure e‑mail system. Great, I'm going to hand it over to Nikema.

>> Good afternoon, everyone. Like my supervisor Jessica said, my name is Nikema. I'm the health data analyst for the state of Florida or the EHDI data coordinator. So our objectives for this research were to examine the Florida EHDI program's outcomes and accordance with meeting JCIH recommendations to determine the distribution of Florida's 2015 to 2016 infant pop ration in relation to the location of local early steps offices. Assess implications for what areas the program may be able to focus on to aid in improving outcomes for our deaf or hard‑of‑hearing infants in Florida.

So the methodology for this research, we used the data from the CDC's or the Centers for Disease Control and Prevention's hearing screening and follow‑up survey. Each state that is involved in this is required to submit this information annually. The CDC HSFS, which is the short acronym for that, those definition that is they termed were used for screening diagnosis and intervention data. We also used the guidelines for the 1‑3‑6 goals as they're termed. Spatial analysis was conducted to determine the distribution of Florida's 2015 to 2016 infant population in relation to the location of the local early steps offices.

The software used in this project was Microsoft Excel for some simple data calculations and we also use ArcGIS Pro which is a spatial analysis tool and software. The population data was collected using the Florida HealthCHARTS data query tool.

So results. This is a lot of numbers, but I'll go through it slowly. So, for 2015 and 2016, we kind of did a comparison, but these are percentages but also counts. I know it's easier sometimes if you can see the number in comparison to the actual percentage to gain a full picture of what we're dealing with here. So, in Florida, we birth roughly 220, a little over 220,000 children each year. We are one of the largest birthing states in the nation. So for the year of 2015, we were 224,273 children. We screened a total of 96.8% of those children. And by one month, which is our one‑month goal, we screened 96.2% of those children.

For our diagnosed by three months, total documented diagnosis we had 89.3%. However, during this year, at the time the survey was required to be submitted, we had a software update with our data system, our EHDI information system, or EHDI A system, so we weren't able to send that information in to CDC at the time.

For our enrolled and early intervention, we had a total of 291 children or infants diagnosed with a form of hearing loss at that time, and by six months we had 59.5% of those children enrolled in early intervention, with a total enrolled being 65.3% of those children diagnosed.

For 2016, the numbers are similar ‑‑ a little bit similar. We have 225,018 births. Of those, 97% were screened. 94.8% of those were screened by one month. So with a total documented diagnosis, 89.2% of those children had a total documented diagnosis. And by three months, we had 86.7% of the diagnosed, whether that was a normal hearing or a form of hearing loss.

So total diagnosed with a permanent hearing loss that year we had 287. Of that, we had 67.2 of those children enrolled in early intervention, and a total of 66.8% of them were enrolled by the six‑month mark.

And then here we have the lost of follow‑up numbers for each year, and that total lost of follow‑up for each category you see there, we'll go a little bit deeper into that in the next few slides.

So 2015. We are focussing here on the 1‑3‑6 goals in the comparison to the national averages. So in to 15 which screened 96.2% of our children by one month, in comparison Ott national average of 95.5%. Again, our by three months number, we were not able to collect that, but nationally, that percentage was 71.9.

The percentage for enrolled and early intervention was 65.3%, and that is of our total children that were diagnosed with a hearing loss. And then enrolled in early intervention by six months was 59.5% of those children, compared to the national average of 65.3%.

So in 2016, we did ‑‑ we screened before one month, 94.8% of those children. By three months, we had diagnosed 86.7% of them again, that's whether they had a permanent hearing loss or normal hearing. And, luckily for IS system did not have a software update that time so we were able to report that number. So enrolled in early intervention, of our children that were diagnosed with a permanent hearing loss, we had 65.3%, compared to the national average of 67.2%, so not too far behind but still we saw an area where we can improve. We haven't ‑‑ we saw an opportunity for improvement.

For our enrolled in early intervention by six months, we had 59.5% of those children that were diagnosed, compared to the national average of 67.3%.

And here we have lost of follow‑up and lost of documentation numbers, and we'll go through this slide and the next are 2015 and 2016 data compared to the national averages. So our screening loss of follow‑up, we did pretty good here. We had 1.5%, that's compared to the .7%, and we want to keep those numbers low. So that is the purpose, lost of follow‑up, you don't really want to have a higher percentage of lost to follow‑up, generally for those who don't really know what that means as far as data goes or as far as outcomes goes.

For the diagnostic lost to follow‑up, that's for children we know did not pass the hearing screening or the second hearing screening and needed a diagnostic evaluation, 7.2% of them, we had categorized as lost to follow‑up and those are various reasons that could be lost of follow‑up generally or a lost of documentation. And it goes in to greater detail. For our early intervention or lost of follow‑up documentation, we had 19.2% compared to the national average of 20.4%.

For 2016, our numbers, again, are similar. Screening, we had 1.2%, compared to the national average of .7%. Diagnostic follow‑up, we had 7.2%, compared to the national average of 25.4%. So we did pretty good, keeping that number low as far as diagnostic evaluation followups.

For early intervention, we had 23.3% lost of follow‑up compared to the national average of 19.6%. And what that means is we don't have it documented in our system that these children were enrolled in early intervention after being diagnosed with a hearing loss.

So this is the very fun part for me because I enjoy spatial analysis. So we have some maps here. And of course, these slides are going to be available if you have any questions, definitely, we want all the questions at the end as well. But I can definitely go in to greater detail. So what this map shows, the ‑‑ points that you see highlighted, the points that you see highlighted in the graph on your left are our local early steps offices. They are separated in to regions, and the counties highlighted depict what counties those offices serve.

And, again, as was mentioned earlier, our early steps program is our Part C early intervention for the state of Florida, and so that's who we refer to and that's who we're able to pull data from on if the children have been enrolled in to early intervention. So those ‑‑ that's what where those are located.

On the map ‑‑ in the map on the right, you'll see, again, these regions and these locations, but now you see it with a layer of Florida's infant population in the year of 2015. So, again, that's that big 224,000 infants born number and so that is pretty much the distribution of what our population looks like in the state of Florida. So I'll talk about this in detail a little bit later in our discussion, but one thing that we want to look at in the future is looking specifically at our children that were actually diagnosed and what that spread looks like and what different factors we can, you know, depict from that and what we can infer by looking at this from a spatial perspective.

And so this is the same ‑‑ this is the same map. However, with the 2016 population. So, again, on the left, we have the location of those early steps offices which did not change. And then on the right we have the 2016 infant population overlaying that. And it's in brown, so anywhere you see you that can't see the underlying color that's where we have like a very large population. So Brower County, Miami‑Dade County, Central Florida, Northeast Florida, you'll see like high areas of population there.

So discussion, what does all of this mean? So when doing this research we saw an area where we could greatly improve, and that's with lost of follow‑up and lost of documentation. One of the purposes for this research was to find where we stand as a state and look at what our numbers already say, what we can do better, and how we can do that better by looking at what we already have to improve outcomes for our children.

So we noticed that, in lost of follow‑up and lost of documentation specifically with early intervention, for our state, in the state of Florida, early intervention is housed under a separate program that is not data that we collect ourselves as far as if they're enrolled. So there's a special entity that controls that information, controls the follow‑up as far as making sure these children are getting enrolled in to services, so we realize the importance of having strong relationships with that program and other stakeholders involved in the process of making sure that these children are getting the services they need.

Early intervention, we talked about the lost of follow‑up and lost of documentation or how we collect that data. We have a little bit of access from that partnership to collect numbers, but we're not involved in the side of the process that actually makes sure they get to the services they kneeled. So as far as early intervention in our state, our Part C, they have a, at this time, and they're working on it, there's a nonintegrated data system. So he is are each of those, from the map you that saw that there were different early steps locations regionally throughout the state, they have their own individual processes as far as they ‑‑ how they enroll a child in to services and anything involving that process, it varies from each location, but they're already reported to the state through the early steps program. That is the varying operational procedures.

So one thing that we are working on, I, myself, and one of my colleagues, we are on some work groups with early steps to strengthen those relationships and kind of provide our perspective and have a voice for our children in the outcome that is we need to see and what we need to do to help them. So that's been a recent addition, us being involved with that program more to provide our perspective and kind of help them as they move forward in bettering their system and their information on how we can be a part of that, to help them, while we also help our children.

So our EHDI IS, or EHDI information system, we have some data fixes. So, of course, in 2015 we had a software update. But we wanted to highlight this because it is very important that data is quality. You want to collect data, of course, but you also want to make sure you're collecting quality information and that you're disseminating it appropriately. So we saw that there was a problem in 2015. And as a result, we put in requests, we talked to our programs, we talked to data system engineers, and we made improvements so we made sure we were collecting a accurate depiction what was actually going on in the state of Florida.

And then, of course, in the spatial maps, you see that we have an interesting shape as the sunshine state. We are ‑‑ you we have offices, interestingly placed throughout the state. We have a large population of children and it's very widespread. And so knowing that that is our setup, we want to look at that and take that into account when we're thinking about if the children are getting services because what we realize is, since we're not following the process of early steps, they're their own separate entity, just because they're not reporting as being enrolled in to services through early steps, that does not necessarily mean that they're not getting services. So we saw that is something that we plan to look to and are beginning the process of looking in to moving forward. We've already started the process, but moving forward, that's something that we're paying attention to. Reaching out to other stakeholders that exist within our state in order to make sure we're collecting all of the data possible and making sure these children are receiving services.

>> Okay. So some next steps. So this is, you know, something that we're working on pretty hard right now. I'm actually going to skip ahead a bullet. So one of the things that we've noticed and what we have to submit data to the CDC, we are we're asked to submit non‑Part C data, and that's something that's been a struggle for our state because we have access to the Part C data, we have some level of access in their data system that we can pull information ourselves, but we don't have any non‑Part C data coming in. So one of the things that we've implemented just recently is we've hired a parent consultant to, she's here, to do a newborn follow‑up caseload of hearing loss children. So I mentioned previously, we ‑‑ we would send a packet of information and to the families and then do a referral to early steps, but we really didn't have any contact with the family after their diagnosis. So our goal is to kind of have the ability to reach out to those families at the time of diagnosis and be able to help support them and encourage them in to early intervention as soon as possible and set them up with the resources that they need.

Another thing, and by doing that, we're also going to be finding out if they're using non‑Part C providers and kind of checking in at different points so that we can kind of manually track that ourselves.

We've also added a diagnostic evaluation piece to our electronic reporting system. So we're hoping that that will give us more timely access and hopefully increase reporting for that three‑month benchmark. And at that same time, as we're rolling that out this year, that's been a big part of our CDC grant, we are really doing a big push to develop materials to provide audiologists and kind of remind them who we are, what we do, and why it is important to report to us that it is not just the newborn screenings that we're looking for, it is that we're looking for the zero to three for all of their diagnostics. So another way we want to do that is kind of coordinate with the Florida's association of audiologists, maybe perhaps present at their conference, and exhibit, and also we're looking at partnering with audiology schools and with the state licensing board.

>> So a few limitations of this research study, I mentioned it earlier, but in 2015 we were not capable of calculating the number of infants diagnosed with no hearing loss before three months due to a software update. In our spatial analysis, Miami‑Dade County, this separates it, and if you're not from Florida, you may not know where that is, but it is one of our largest birthing counties in the state of Florida. So early steps, they separate that in to two different service areas, north Dade and South Dade. However, when it comes to spatial analysis in the county population as we collect different Florida charts, they do not separate out the population by north Dade and south Dade. So it was an issue this time around. However, in future research, we plan to do that spatial analysis and have population data by zip code. It will take a little bit more work, but it is possible and we'll be able to look at those numbers more carefully and closely then.

Statistics in this research presented are specific to the state of Florida so results are not generalizable. However, the methods can be used to duplicate this type of study for other states and territories. So that's one major take away we want from this presentation, that these are our numbers. However, the same type of research and the same type of critical analysis of where you are and your program or where you are in any stakeholder program, any program with a vested interest in this community, there's always time for you to look at your research and your data, critically, to see what you're currently doing and how you can improve for the children.

Conclusions. So we realized, like we knew, the importance of stakeholder involvement in the EHDI process and, like Jessica said, we've done a few things to make sure that we're strengthening relationships where it is partnering with early steps or is joining in with the schools, the audiology schools, and things like that. So stakeholder involvement is very important. The importance of data quality for improvement of outcomes. If you're not collecting proper data, if you're not collecting accurate data, you will have a problem with when it comes time for planning and seeing where you are.

The use of creative methodologies in practice‑based research. Being the state and being the one that is are actually doing the follow‑up, that are actually reaching out, even at the level of screening, you're in a ‑‑ you're in a sweet spot. Some people just see numbers all the time. They don't have a connection to the people you're serving, they don't understand the importance, so it is really important in these settings to do this type of analysis so people can really understand, because no one can talk about your program or how you do things better than you can, because you have firsthand experience with it. Further research is necessary to examine statistically significant factors that affect EHDI outcomes and geographical trends in the EHDI outcome data.

These are references, which this will be available.

More references. That do you all have any questions? Okay.

>> (Speaking away from microphone)

>> So in this study we did not but that is going to be a part of the next study when we zone in on just those children that were actually diagnosed. So we do collect that data. We do collect demographic information when that data is collected through our partnership with our I have the I have the vital statistics in the state. And so we'll definitely have access to that for the next study. Any other questions?

Okay.

(Applause)