>> Good morning, everybody. Thanks for being here. We're going to get started. I would like to introduce our speaker. And I'm also going to remind you at the end of the session to please go to the app and complete your evaluation for this session.

With that I'll turn it over.

>> Good morning. I am with the CDC EHDI team. I hope everybody is having a good time at the conference. Today I want to start with background information before getting to the presentation. So this is the funding state EHDI program, diagnostic and evaluation information on babies born in the state territory.

The data collection was through the anual hearing screening and follow-up. The data is aggregate, and because the data is aggregate, there are limitations that includes detailed analysis or follow babies through the EHDI process.

>> Good morning. I guess I'll start over again.

My name is Suhana aham, I'm with the CDC EHDI team... should I keep going?

>> Should I go ahead and speak?

>> SUHANA: Hello again. So I was saying the state funding EHDI programs since 2000 to collect information on babies born in the states and territories, screening and diagnostic and integration and enrollment information, and always do annual start by hearing screening and follow-up study. It's aggregate data, because it's aggregate data there are limitations, detailed analysis and follow babies through the EHDI process.

So in 2010 we started a pilot project with a few states to begin reporting level data, and we saw it was very beneficial. We were able to do detailed analysis and learn a lot from the EHDI informing.

So in 2020, the cooperative agreement, the CDC found 39 states and territory EHDI programs to report level data. So today's presentation is going to look at the 2020 information that the recipients provided to the CDC. So how we share what we were able to learn from the data.

You probably have heard many times already about the 1-3-6. It's important to detect permanent hearing loss as early as possible to minimize the risk for developmental delays.

So I mention that, and the objective today is to look at the intervention for babies born in 2020 using level data provided by 39 EHDI programs -- I'm sorry, 37.

States that were having data quality issues and did not include the analysis. The screening is doing so well, focusing on diagnostics and intervention areas.

So the EHDI programs, they extract an individual level information from their surveillance system, and the personal information, like the names, address, Social Security numbers were removed from the data files, and this study population in this presentation of infants born in 2020, babies who died or moved were excluded from the analysis so we don't have the data when moved for the benchmark age calculations.

So the study population consists of about 223 infants, and covers the evaluation area. Among the study population, about 44,000 did not pass the final hearing screen. About 31%, which is about half -- 51% documented to be evaluated, and I used the term "evaluator," because those are the information we have.

There are some who probably got evaluation, but maybe it was not documented or reported, which is why we include audiologist -- encourage audiologists to report diagnostic results to the state EHDI programs.

We have 51% were evaluated, and among the infants evaluated, 71% was by the recommended age.

And 3600 had prevalent hearing loss and 66% of them were diagnosed with three months of age.

Now, looking at the enrollment, we were able to see that among 3600 infants with permanent hearing loss, 52% were enrolled in Part C. Of those enrolled, 70% marked the six-month benchmark.

We also looked at the different demographic factors to predict diagnostics and enrollment into intervention service.S so the babies who did not pass the final hearing screen, looking at the diagnostics first, we saw that among the NICU infants, them getting diagnostic evaluation is 70% higher than non-NICU.

We also see the higher the mother's education, the more likely of the infants getting diagnostic evaluation compare to mothers having below high school education. We see that the mothers with Bachelor's degree and beyond are two times fold likely of their infants to get diagnostics compared to moms with below high school education.

We also see that infants of Asian mothers have higher odds of receiving diagnostics compared to infants of Hispanic mothers.

Now, looking at enrollment intervention services, we see that the odds of infants being enrolled in intervention services is 20% than non-WIC infants. We also see mothers have bachelor degree and beyond, the odds of them being enrolled is 80% higher than infants of mothers having below high school education.

The year 2020, the babies being evaluated before three months of age. For example, the babies born in January who did not pass the final hearing screen ideally they should be evaluated by three months. February babies should be evaluated by May and so forth.

So 2020, the year of the pandemic, we see the lowest rate of evaluator before three months among the February babies. February babies, 49.7% were evaluated by three months of age. And as we go through the year, we see the rate gets better and better.

I noted here generally 20th, that's when the first case of COVID-19 was detected in the U.S. And March 13 it was declared a national emergency in the U.S. So that is relevant here, because it shows that pandemic dates have an impact on EHDI services.

And here is the early intervention before six months of age, and also received here most impacted, about 60% were enrolled by six months. But then it gets better. And then from June we see that it declines again a little bit, like the June babies with permanent hearing loss, they should be enrolled by December. July should be enrolled by January.

So they seem to be maybe related to the winter of 2020 when the new variant was circulating and prevalent. There was a new variant going around, I think delta.

So that could be the reason why we see decline between June and October babies.

So in conclusion, I want to say individual level datasets provided by recipients in the cooperative agreement, they provided a lot of learning opportunity and were able to do so much with that. We were able to do detailed analysis and learn a lot from the data.

So thank you to the state EHDI programs who put a lot of time and effort in putting together the datasets and reporting them to the CDC. It's been very beneficial.

The findings from the analysis allowed for us to identify the populations that the EHDI programs partners can consider to target to improve had equity and assets to EHDI services.

Partners strategize resources in a disaster in the future. You can see a little bit more in the pandemic, like audiology. So that is an area worth exploring for the future.

We also see from the analysis that more work is needed to increase receipt and timeliness of infants getting important follow-up services to minimize risk for developmental delays.

So that's it from me today. So how much time do we have?

We have about six minutes. So I would like to...

We have about six minutes. I would like to get -- give the state EHDI programs the opportunity to ask any questions.

>> MODERATOR: If you have questions, raise your hand and I will bring the microphone to you so that CART and the interpreter have access.

>> SUHANA: Questions or comments?

>> AUDIENCE MEMBER: Our newborn hearing program continued on for the screening part without interruption. But for the babies that failed the initial screen, we got tremendous pushback from the parents about bringing the child out of the house for the follow-up diagnostic.

It took us almost a year to really catch up with the babies that failed the previous year. And we're still not up to where our normal caseload is with regard to infant hearing follow-up. We're getting close, but the fear is still there, at least to some extent, and parents are still very hesitant about bringing the babies out to a clinical setting.

>> SUHANA: Yeah, there are studies that say there are families who either cancelled or delayed in-person appointments because of fear of exposure.

>> AUDIENCE MEMBER: Thank you for this. The data are fascinating. Of course, we all want it. We want to see it. Is it available yet? And is it being published anywhere? Or can you just make it available?

Thank you.

>> SUHANA: Data published on the website or journal? Okay. A few months ago we published information, the pandemic impact on EHDI services among four states. Have you seen that publication?

Yeah.

So we might maybe replicate using certain state EHDI programs.

>> AUDIENCE MEMBER: I feel like the other group of people that would really appreciate having these data are the people in the early intervention Part C state programs, and I would think both EHDI and Part C would want to use these data to see how close we're coming to our goals and what we need to do, and as you said, most importantly, looking at the equity issues that are embedded in the data.

So I feel like it's just a wonderful piece of evidence or evidences that people could use today.

>> SUHANA: Thank you for that comment. I will try to work on maybe putting together a manuscript based on this presentation.

>> AUDIENCE MEMBER: Good morning. Did you guys look at which states fared better than other states amongst the jurisdictions that you guys did -- pulled the data from?

>> SUHANA: I would say the CDC EHDI workshop we have state-by-state. Have you seen those on the website, how the state is doing in terms of meeting the national benchmarks?

>> AUDIENCE MEMBER: Okay. So it is there?

Okay.

>> SUHANA: Any other questions?

>> AUDIENCE MEMBER: I have a question/comment, maybe.

For this presentation, you used the percent diagnosed by 90 days of those with a diagnosis. Which is different than the HSFS. So if people go to the CDC website to look at timely diagnosis data, it's going to look very different. I just want to... unless there's... because there's not I EHDI data up there at all. For us, if we're looking at state data and looking at it you know, timely diagnosis of those with a diagnosis, yeah, we're up over 70-some percent. But if we're looking at timely diagnosis of those that needed diagnosis, so we're including all the loss to follow-up cases, then we're down below 50%.

So I just want to caution sending people to the website to look at data, because it's going to look very differently.

>> SUHANA: So on the webpage, the diagnosed by three months of age, the numerator is all the babies diagnosed by three months and the denominator is all the babies who were diagnosed -- we also have another column where the denominator is infants not passing the hearing screen. We have two different formulas.

>> AUDIENCE MEMBER: I'll have to look more closely at it then.

>> SUHANA: I can send an email to show you which columns I'm talking about.

>> AUDIENCE MEMBER: So I have a question and also a comment. So the question is for your study here, we know the states, it's regarding the timeliness and... I mean, there are a lot of variation, if you look at the EHDI data, some states are doing very well and some states are doing not that well. So in your analysis, have you adjusted for this kind of heterogeneity thing in the data? That's my question.

And then my comment is, for the CDC data, I understand what you said about the -- for example, when you look at the diagnosis you have a follow-up rate and also the diagnosis within three months of age.

So it doesn't have a column that it gave you the product of those. You can easy calculate that, you do a product of those two, and then you get the... then you get the values for the 1-3-6, the real 1-3-6 indicator benchmark. So my suggestion is to -- is it possible to add that in the CDC data table? So we have the number to go by when we reported the data in our grant application and progress report. Because right now I don't think it's included in the EHDI data on the website. Thank you.

>> SUHANA: If you don't mind, could you repeat the second one?

>> AUDIENCE MEMBER: The comment? Yeah, the comment is... yeah, it's about the CDC data. It's already on the website. So you have the percent of diagnosis completed, evaluation completed, and also among those completed, what is the percentage of them completed within three months of age?

You have two separate ones, but you don't have the one that, among tall babies needing evaluation, they are completed within three months of age.

>> SUHANA: The diagnostic summaries, the website does have that information. We have a column of a total who did not pass the hearing screen, how many were evaluated and how many were evaluated by three months of age. Is that what you're talking about?

>> AUDIENCE MEMBER: Yeah. So when you look at the percent evaluated by three months of age, so in the denominator, you know, that is the number of babies who did receive diagnosis. But when you look at the 1-3-6 benchmark, on the two, the denominator is supposed to be all babies who failed, rather than those babies who received diagnostics -- I don't know if this makes sense.

>> SUHANA: I think there is a comment.

>> AUDIENCE MEMBER: I just pulled up the data table, and for 2020, they do have in the diagnostic breakdown, the last two columns show those different groups. One is of those diagnosed, and one is of those needing diagnosis. So, for example, in 2020... whoops, where did it go now?

The national... my computer is not working.

The national average of those diagnosed was 60.6% and the national average of those needing a diagnosis was 36.3.

>> SUHANA: Thank you, Kristen.

Any other questions?

And you can reach out to me. Please feel free to send an email at any time.

It was a pleasure to be here today. Thank you so much.

>> MODERATOR: Thank you, everyone, and please be sure to fill out the evaluation for this session. Enjoy the rest of the conference.