

GUNNAR THURMAN: You should be OK to leave it off.

WILL EISERMAN: OK.

Suhana, you will want to click the slideshow again to get it started. Yes. Great.

SUHANA EMA: Should I go ahead and get started?

WILL EISERMAN: I will do an introduction first.

Well good day everyone. I would like to welcome you to today's webinar entitled: EHDI After Newborn Screening: the status of meeting the diagnostic evaluation by three months of age and intervention enrollment by six months benchmarks among babies born in 2021 and 35 states.

My name is will Eiserman, and I am the associate director of the national Center for hearing assessment and management known as NCHAM at UMass state -- Utah State University. NCHAM as you know serves as the EHDI national technical resource Center or the EHDI NTRC. We sponsor a variety of different webinars like the one we are having today.

Today's webinar is being recorded, so if anything disrupts your full participation, it looks like our video has suspended for our interpreter, so I'm going to pause for a moment.

GUNNAR THURMAN: William, this is Gunnar, it might just be you.

WILL EISERMAN: OK, good. If it happens on your end just let me know.

So we are going to have this webinar recorded, so if anything disrupts (audio issues) your full participation in today's webinar, or if you think of somebody who might benefit from today's presentation, who is not attending live, you can direct them to our website infant hearing.org and a couple of days, probably by the beginning of next week, and you will be able to stream today's webinar and share it with whoever you would like or review it again.

I want to give a shout out to our captioners, our captioners and our interpreters today. Thank you for your talents and availability to help this webinar be as accessible as possible.

After our presenter has collated the remarks for today, we will open up the floor to questions. So hold your questions until we open up the floor for that, and then I will read the questions so that our presenter has an opportunity to think about them and then give a response.



So, our presenter today is Suhana Ema who serves as an epidemiologist with the CDC EHDI team. She is responsible for analyzing EHDI data and disseminating findings with jurisdictional EHDI programs and partners. She also provides technical assistance to EHDI programs to improve their program and tracking, and surveillance work. She holds a Masters of public health from the University of Georgia.

Suhana was born with severe to profound hearing loss in both ears, and wears hearing aids. She is fluent in American Leg Which Ad Lib. Reads As Well. -- Americans I Leg Which Ad Lib. Reads As Well.

We will turn the microphone over to Suhana, thank you for being with us today and sharing what you have for us today.

SUHANA EMA:

Thank you so much well for the introduction.

Hi everyone, I am Suhana, thank you so much for being here with me today. Let me just adjust my screen a little bit.

So I am with the CDC EHDI Team thank you for having me today. I will be presenting on the status of meeting the diagnostic evaluation by three months of age and enrollment interventions by six months of age among the babies born in 2021 and 35 states.

So according to the CDC National data, about one in every 500 babies born is deaf or hard of hearing. And this is a public health issue because undetected hearing loss can have adverse developmental effects that can have lasting impact on the children.

So to memorize the risk for developmental delays, it is recommended for babies to get a hearing screen before one month of age. And those who do not pass the hearing screen will get a diagnostic evolution by three months of age. And those who have prominent hearing loss should enroll in intervention services before six months of age, and that is known as the 1-3-6 benchmarks.

So the hearing screen (Indiscernible) is doing so. Over 95% of the newborns that are hearing screened before one month of age, the majority of them in the hospital before they go home. So for this study we decided to focus on the 3 to 6 benchmarks.

Under the current CDC (Indiscernible) agreement, 35 additional program support limited and (Indiscernible) data on babies (Indiscernible) and specify per year.

So in the study we used data that will reported by the recipients this year, and babies born in 2021.

Because of quality issues (Indiscernible) for recipients are not included in these analysis, this analysis includes 35 recipients.



So in this study were excluded babies who died or moved out of their state or territory. So the analysis includes 2.1 million babies, again that is (Indiscernible) additions. The analysis was done using SAS 9.4 software.

So we learned that among the 2.1 million babies born in 2021, 37,000 babies failed the hearing screen as final outcome. That doesn't include (Indiscernible) we did not get a hearing screen due to be referred directly to diagnostic evolution.

Among those 37,000 babies, 59% received follow-up diagnostic information where diagnosis was made of (Indiscernible) hearing, transit hearing loss or permanent hearing loss. The other 40% did not get sent by an audiologist or did get sent by an audiologist but do not yet have a confirmed diagnosis.

In addition, among 37,000 babies who did not pass the hearing screen, 45% (Indiscernible) benchmark. As mentioned earlier, it is recommended to take a diagnostic evaluation before (Indiscernible) if they do not pass the hearing screen.

Here we can see on the slide the age of diagnosis is calculated by taking the date of initial confirmed diagnosis minus the infant's date of birth. That gives us the age in days.

(Indiscernible) confirmed diagnosis is defined as the first date where confirmed diagnosis was made. So, it could be normal hearing, permanent hearing, loss or transient hearing loss.

Sometimes (Indiscernible) have multiple evaluations, so we take the date of when was the first confirmed diagnosis for assessing the three-month benchmark.

So for an example, if the infant cut three diagnostic evaluation, the first one doesn't have a confirmed diagnosis but the second one did, we will use the data for the second one when calculating the age.

If the baby was diagnosed before three months of age, the baby marks a benchmark. If beyond three months, the baby did not meet the benchmark.

In this analysis we saw that the mean age of diagnosis is 77 days, and the median is 52 days.

And looking at the intervention enrollment. In 2021, among 35 additions, we saw about 3600 babies would document it to have permanent hearing loss. So among those babies, 56% were documented to be enrolled in intervention services. And that includes both Part C and non-Part C.

So among those babies with permanent hearing loss, 39% met the six-month benchmark. The age at enrollment is cocreated by the (Indiscernible) in Rome it Part C or non-Part C minus the date of birth, that gives the agent days.

If the age is within six months of age the baby next the benchmark. If beyond, the baby did not meet the six-month benchmark. So again, that's for 35 (Indiscernible) age of enrollment with babies with



permanent hearing loss 159 days and the median is 120 days.

So we performed multiple logistic regression to predict the receipt of likelihood of infants who did not pass the hearing screen and are (Indiscernible) enrollment for intervention enrollment for babies with permanent hearing loss.

So first we will tackle the diagnosis. We saw the (Indiscernible), we see that diagnostic evaluation is 50% higher than for non-NICU infants. We also saw that the WIC status is 30% higher than non-NICU babies.

Not surprising we saw the higher the (Indiscernible) addition the higher the odds the baby getting a diagnostic evaluation compared to babies whose moms had (Indiscernible) education.

We also thought the babies of Asian members had 20% higher odds of receiving diagnostic evaluation compared to babies that -- babies of Hispanic mothers.

Now looking at the intervention enrollment, we saw that the (Indiscernible) includes babies being enrolled in intervention services is higher – 10% higher than for non-NICU babies. (Indiscernible) shown babies that mothers have higher (Indiscernible) enrolled in EI compared to babies with high school education. But the findings are consistent with the previous information.

So that the summary of the 2021 data or 35 additions, we can see that individual levels, data provided great opportunities of analysis to do detailed analysis and learned a lot from it. It allows for finding – Mike identifying the gaps and needs of improvement.

The findings allow for specific populations that may experience (Indiscernible) targeted to include equity and access to services.

The findings also show that the whole world needs to increase, EHDI -- receipt and timeliness of advance getting important follow-up services. It is important for infants to get time sensitive services to many mass risks of developmental delays and ensure they are able to reach their maximum potential.

So the CDC would like to thank the recipients for their hard work and reporting this data. We would not be able to do this analysis and learn so much without their support.

So that is all for me. I would like to open the floor to everyone here. Does anyone have any questions for me today?

WILL EISERMAN: Thank you so much Suhana.

This is will Eisenman again, from NCHAM, and the EHDI NTRC.

We have one question. And I think you -- and a thank you from this audience member.



What were the screening tests that were used and was it a one phase or a two-phase screening protocol?

WILL EISERMAN:

Suhana, you are muted. Start over please.

SUHANA EMA:

I was saying that some states do one stage, and some due to stage. For data analysis, we take the results and the final most recent hearing results.

WILL EISERMAN:

This is will from NCHAM again. The next question is: what do you attribute the higher rate of follow-up found among families who were enrolled in WIC?

SUHANA EMA:

That is a good question. I would love to open up for discussion why we are seeing that babies who are in world in WIC are more likely to get a follow-up, to non-WIC. If anyone would like to add comments to this one.

WILL EISERMAN:

If anyone has a suggestion of how to interpret that finding, it sounds like Suhana and her team are open to hearing what you think that means, from your own experience, and perspectives.

Let's see, Suhana, if anybody responds to that. And we can return to that question.

The next question is: where the Asian babies receiving early intervention services lower than the white babies?

SUHANA EMA:

Let me check. That is what I am seeing here. Yes.

WILL EISERMAN:

Yes, returning to the question about WIC. One of the participants is saying do you think there is a connection to the maternal health programs themselves?

SUHANA EMA: Could you repeat the question please?

WILL EISERMAN:

We are returning to that question about what do you attribute the higher rate sound... Follow-up found with families who are enrolled in WIC. Do you think maybe it is related to the maternal and Child health program itself?



SUHANA EMA:

I mean it is possible. I do not have all of the answers. That is a great discussion to discuss amongst (indiscernible). That is what we are seeing in the data. It is very interesting that the WIC babies are more likely to get follow-up services compared to non-WIC babies. Would anyone like to add to this one why they think the WIC babies get more?

WILL EISERMAN:

It certainly highlights a potential strategy for EHDI programs who are looking for way, to increase follow-up. By perhaps engaging more actively with WIC programs, and promoting WIC services for families who qualified, or are eligible for those programs.

Another question, did you track the etiology of reduced hearing levels for the children in your study?

SUHANA EMA:

Yes, as of right now that data collection, we do not collect the etiology (indiscernible) for children in our study.

WILL EISERMAN:

OK. Is there a way to find out which states are included in your study?

SUHANA EMA:

Yes, it is a long list. Under the cooperative agreement, (indiscernible) due to quality issues, the analysis includes 35 studies. I am happy to provide a list of those 35 state names that were included.

WILL EISERMAN:

This is will again. Should anyone who is interested in a more detailed report contact you via email, Suhana, to get information like that?

SUHANA EMA:

Yes, absolutely. I welcome emails. Anyone can send me emails, and ask questions that they have.

WILL EISERMAN:

OK, great. Gunnar, could you put Suhana's email and the chat please so that we know how to contact her.

The next question is: from my experience, (audio issues), returning to the WIC families, this person is saying from my own experience I think that WIC families are more inclined to respond to EHDI program initiatives to inform parents to have a follow-up.

Another person is saying perhaps because there are other supports in place, to lead the family, that might be another explanation of WIC follow-up.

There is something here is in there about what is happening withWIC families, that we could replicate for families who.... Something unique is happening there that is worth knowing more about.



I think more eyes on the baby, more likely they are to be identified. Families seen in WIC clinics are followed closely by caseworkers. When a child is identified as deaf or hard of hearing, they may have continued follow-up actions for that child.

Another person is saying, I wonder if families receiving WIC have another variable such as intrinsic motivation, or access to high-quality primary care, in which the provider is likely to share resources, working in their favor.

Another person is surmising, could it have something to do with insurance coverage?

Another person is suggesting, these are all great hypotheses... Could the WIC findings be attributed to WIC providing accurate demographics? WIC families keep their contact information current.

Another question, Suhana. Can you explain when is enrollment? As soon as eligible, or as soon as the IFSP is signed?

SUHANA EMA:

For the analysis, I use the date of IFSP, the date when the IFSP was signed. If that is not available, then I use the date of when the family was enrolled in (indiscernible).

Usually IFSP indicates participation. Did that answer the question?

WILL EISERMAN: Gunnar, I experienced a technological glitch just now, did you?

SPEAKER:

No, it is on your end. Everything it OK. Looks like will might be having some internet issues.

Suhana, if you click the Q&A button, at the bottom of the screen, you can see the questions, if you would like to answer them yourself.

The ones down at the bottom, should be more recent.

WILL EISERMAN: I am back. Can you hear me?

SPEAKER: Yes I can hear you.

WILL EISERMAN: Sorry, I was kicked off.

Here is a question for you: was there any data that shows the mother's ages in the WIC program?



SUHANA EMA:

We do not have that data. The mother's age, (indiscernible) in the WIC program.

WILL EISERMAN:

I am having a problem. If you could pick up reading the questions from where Karen (indiscernible) comment is, and go down from there.

SPEAKER:

I can take over from there. More comments about the WIC comment. Sara says she works at DPH, and WIC personnel are in her building. We interact often, and they refer to us as needed.

Lisa says by way of information if a family is on WIC they have regular interviews with nurses. I believe on the WIC management team. Parents have to take their families to (Reads chat)

We have another question here: linkage to maternal and child health programs perhaps this is the same for NICU infants? Were they enrolled in a perinatal program, development follow-up clinic, or are infants enrolled in WIC? NICU grads are at risk... (Reads chat).

A new question here, from Holly. What kind of intervention services the children receive, specifically, and did you collect info on whether it was a signing, queuing, or listening and spoken program?

SUHANA EMA:

We do not collect that information about specific (indiscernible).

SPEAKER:

Great. Another question here that just came in. You report for 35 states, which is lower, substantially fewer than states reporting from 2014 to 2019. Do you understand the reason for this drop?

SUHANA EMA:

Could you rephrase the question, I am not understanding this one?

SPEAKER:

We can see if they can rephrase it. Another question, do you think there would be a difference in the data if measured from eligibility date of enrollment instead of IFSP Part C?

SUHANA EMA:

Could be. I honestly do not know. I would think it would be different if we go by eligibility date, instead of the enrollment into IFSP. Let's say there are 500 babies eligible, but 300 are enrolled in IFSP Part C, that would be difference in the data. We do not collect eligibility dates, at the moment.

SPEAKER:

Great thank you. It looks like that is all the questions we have listed.



I will go ahead and wrap things up for us then.

Thank you Suhana for your presentation today. Just so everyone knows, I will be posting, in the Chatfield, a survey that you can fill out, if you would like to give us some feedback. If you do that, you will receive a certificate of attendance. That is in the chat field now.

I will go ahead and leave the room open for a couple of minutes. Our presenter and accessibility providers are welcome to head out if they would like. Thank you again everybody.

SUHANA EMA:

Thank you so much for having me today. It was my pleasure to give the presentation today. My email address is on the slide, so please reach out if you have any follow-up questions on the webinar. Thank you so much.

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