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Baby Flow through the EHDI System: An Examination of Data and Performance Measures

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(Captions provided by a live Captioner.)

>> It is 1:00 o'clock. We're going to give everybody an extra minute since we kind of got moved around.

All right. I want to make sure this is on. Welcome, everyone. My name is Ericka Odom. You've seen me a time or two at this point maybe. I am the CDC EHDI Team Lead. Today I am presenting with my colleague Corey Lipton. We're going to be talking about Baby Flow Through the EHDI System. We're going to talk about the EHDI data. During this presentation we're going present some definitions. We're going to look at numerators and denominators. At the end we will have a specific example to work on together during a bingo game.

All right. I have two computers. One has my notes. I'm going to get this straight. So this is our disclaimer. You can read that. Just so you know that the data that we're using here is, I believe it is the 2021 data. The data should look pretty familiar to you. These are our learning objectives. I will give you a minute to read those.

All right. Again in our agenda we're going to look at why is this important to look at these two different definitions. Looking at these numerators and denominators. We're going to look at baby flow through the 1, 2 and 3 months. Early intervention by 3 and 6 months. Then take the information that we learned together and apply it to case study looking at lost to follow up and lost to documentation.

Why is it important to look at our EHDI data? It is not just numbers that you're reporting. They represent the lives of babies. We always try to keep that in mind. I know that sometimes we can become disconnected from the lives of families and babies. If you are looking at the 1s and 0s. I like to keep that in mind using this presentation. Using data there is many ways to analyze data and different ways to get and ways to gain insight. We're going to talk about two specific ways today. In particular CDC focuses on surveillance efforts. Specifically looking at those 1, 2, 3, 6 benchmarks to understand who is eligible and how many within the eligible population receives recommended services and whether or not they receive those services on time. Again, CDC we're looking at the eligible babies. EHDI is look a unique data set. It allows us to look at health disparities and you can use it to lost documentation to help us understand these disparities. It is our aggregates data level data and roll that up to national numbers. Then we have the iEHDI data that looks at the individual events and gets very specific socio demographic information about these babies. Now we're going to move on through the baby flee through the 1 ‑3 ‑6.

Interpreters, if you have any questions just feel free to stop me during the process and ask me to clarify. The 1 ‑3 ‑6 benchmark all of us are familiar with. All infants should have their screening by one‑month of age. All infants that do not pass their hearing screening should pass the diagnostic evaluation by 3 months of age. We say should but we know they don't receive that by 3 months. For 6, all infants diagnosed with permanent hearing loss should be enrolled with early intervention by 6 months of age.

Knowing these definitions helps us determine our denominators as we move through the examples. We want to level set and say we're looking at this from an eligible babies surveillance in public health perspective. Now we get to look at this definition of eligible versus served. This is how we're going to set up talking about our denominators. So at 1 month all infants are born. At 3 months it is all infants that do not pass their hearing screening that we're trying to identify. By 6 months it is all infants diagnosed with permanent hearing loss.

Public health surveillance focuses on eligible babies. Those babies that are eligible to move on to the next step in the EHDI process. The second way of looking at these denominators is those babies that actually receive the services. Those are two separate denominators. Those that are eligible and those that should move through the system and those who show up in the system and receive those services. So we will distinguish between eligible denominator and served denominator as we go through the 1 ‑3 ‑6 benchmarks. Everybody feel comfortable with that so far? Yes, I see some thumbs up. I can see some head nods. I want this to be a little bit interactive and us to be able to take our time through this so that we all kind of have the same knowledge. Okay.

Who is in the denominator? It is not just data flow but baby flow. So we will refer to the slide throughout the presentation. I want to be very clear about how CDC views babies moving through the EHDI system. I'm going to go ahead and click through this, so all the pieces of the pictures show up for you. Then I'm going to talk about it. I'm sorry. Following a baby through screening and early diagnostic and early environment requirement to detail. CDC focuses on eligible babies. The focus on the slide is not the ins or percentage but the flow of babies eligible to access of services in the next stages of the EHDI system. From CDC's perspective we want all babies born to be screened. We typically call them eligible births. Closely align from the data that we get from vital records. This has been the denominator for hearing screening. Of those EHDI births, about 2%. You see that on the top of the first circle are referred to diagnostic evaluation either through direct referral or eligible because they did not pass the hearing screening. In this example, the 63,000 babies you see at the top that says diagnostic evaluation.

This represents the denominator for hearing diagnoses or diagnostic evaluation. Of the babies that receive a referral for diagnostic evaluation, 10% have a permanent hearing loss. It should be enrolled in early intervention. You see that at the bottom of the pi chart in the middle. This is the denominator in enrollment in the early intervention in the next step in the process. You will see about 10% of that 63,000 is that 6, 518. Those are the babies in the early intervention.

Now we're going to go through the screening of 1 month and eligible babies versus the babies who are screened. I'm sorry. Not screened but served. Okay. So this is the definition of screening by 1 month. We're going to point out the numerator and the denominator and you will see highlighted the eligible population, which is the CDC recommended definition. We're looking at this as a public health surveillance perspective and want to look at all eligible babies. Taking a look at screening by 1 month, across both the quality measures for eligible population versus served population the numerators are the same. So the number of infants screened by 1 month of age is the numerator. The denominators differ slight for one‑month. CDC we report the number of EHDI births and the infants eligible for EHDI screening. For served the numbers births with screen or the number infants with a test are reported. Of those screening are only about 2% difference as you will see as we move on to the next slide or the next step through the process. The denominator begin to diverge a lot. By as much as 40%. We want to really distinguish between these as we move to 3 months and 6 months.

Any questions so far? If not we will move on to the next slide. Again, just a reminder. This is the population we're accounting for in the denominator for screen by 1 month. That is all births reported by EHDI.

And now we have just showing you the formula as written out on the prior slide. Now I'm going to step you through a visualization to demonstrate the difference between the formulas. This is using our 2021 hearing screening and follow up survey data. So we have a numerator listed at the top in purple. This numerator is the same across both formulas. That is about 3.4 million. Less orient you to the babies now on the screen. They are green and yellow babies. The green babies represent infants that are born and screened, while the yellow babies are those born but did not receive a hearing screening. For this example, that is a total eligible 3.5 million. I'm not going to repeat the rest of the numbers. About 3.5 million eligible to be screened. This is the CDC recommended denominator. This results in a 1-month benchmark of 95.5%. That is showing at the right. I know you're used to hearing a higher number. Again, if we look at eligible babies based on the CDC definition of those reported to the EHDI system and you look at the numerator and the denominator you do that division you get about 95.5%. All right. Now we're going to move on to the served.

>> I have a question. So the yellow is not yet screened. Do we know why they are not screened? Is that why that was delayed?

ERICKA ODOM: It is a variety of reasons. If you think about the screening or follow up survey it is sent in November, January 15th of each year and so by that time you have some babies that are just not in our system yet. They may have been babies that they didn't get information on right away because they were sick or in the NICU.

I'm sorry. We need the microphone.

>> This is Gina from Michigan. The 70 eligible is that by 1 month in age?

ERICKA ODOM: That is in total.

>> Thank you.

>> Hi, Mary Ellen. I have a question. Two‑fold in that 70,000 eligible where are the in-home births following in that area?

ERICKA ODOM: They could receive it by the one‑month benchmark or not. They're all in the eligible population. Any baby born and received in the EHDI system, and you reported in the CDC that's all the babies. The 3.5 babies.

>> Say you have eligible babies. Maybe they lasted three weeks or whatever and had a demise, where do they fall?

ERICKA ODOM: They're in there too. It is a small percentage, but we want to account for all those babies. Any other questions? I think this is really good because we have to level set. If there are any other questions please do raise your hand.

>> So that sounds like at least 90,000 or so kids are ineligible. Would you mind going over what the CDC calls ineligible or health reason why they can't be screened? What is eligible and what is ineligible.

ERICKA ODOM: I didn't necessarily say we didn't have ineligible babies. We just say that we have babies that need to be moved and seen throughout the system and based on what you all report. That 3.5 million babies is all of the babies that are reported to the CDC system. And so those that are yellow just didn't receive a screening. Based on the data that was sent.

>> I'm sorry. I'm looking at this again and seeing screened by 1 month of age. Included in that 90,000 are children that were screened just past 1 month of age. Is that what I'm hearing here? If you take 3.5 minus 3.4 minus 70 you're going to end up with somewhere around 90,000. I'm trying to figure out where those 90,000 kids went. Basically some of them are screened after 3 months of age. I don't know what that number is. 90,000 kids are getting screened after 1 month of age?

ERICKA ODOM: After 1 month.

>> Thank you. Sorry.

ERICKA ODOM: Okay. Any other questions? So we're going to move on. Okay. Now we're going to look at the served population. We just got done with eligible. We're going to move on to served. The numerator again is the same. This time we only have our green babies. We don't have those yellow babies anymore. Our green babies for the denominator are those infants that were born and screened. So the dividing the numerator by the denominator we get that benchmark, one‑month benchmark that you're used to hearing. That 97.4%. Those are infants that end up showing up in your data systems as being screened. Okay.

Now we have both of the formulas side‑by‑side. You will note there are about 70,000 more babies in the eligible populations denominator. In public health surveillance we think this is important to account for all of the babies that we can account for. The JCIH guidelines said all infants need to receive a screening by 1 month of age. We know who does and who doesn't. By eliminating by this benchmark the numbers are not different. It is a about a 2% difference. We start to see bigger differences and we move through the EHDI process. We're going to move on to the 3‑month benchmark now and we're going to see those bigger differences. Okay.

>> Thank you, Erica.

COREY LIPTON: My name is Corey Lipton. I work in the CDC with Erica. If you have questions about the 1 month please go ahead and raise your hand. Okay.

Oops. I'll speak into the mic.

Taking a similar approach we want to look at the formulas written out first. We're looking at that eligible population versus the served population. Diagnoses can fall into the categories of normal, permanent or transient hearing loss. When you see the word diagnoses there, that's what we're talking about. Those three different categories. For the denominator CDC includes all infants eligible for a diagnostic evaluation. It is our infants that did not pass their hearing screening or were referred straight to diagnostic evaluation. I will give the caveat we will put not passing hearing screening. Please note that the straight to diagnostic evaluation infants are included.

For the served population are those with the documented diagnostic evaluation. We're going to show our pie charts again. Again we looked at hearing screening. That was our birth population for our denominator. Now that 2% circled in red. That's who makes up the population for the 3‑month benchmark.

Here is where it will start to get a little more complicated. As you can see we have the stop light babies. Three different colors.

At the top we have the numerator shown in purple. This is the same across both the eligible and served formulas. And again I think it was a good question earlier. This numerator is those that received a diagnoses by 3 months of age, but we do have infants that received a diagnoses after that timeline. For purpose of this formula we want to see who is getting it by 3 months. Now to go through our stop light babies. We're going to start with the screening population now that we've moved on from birth. As we know, most infants will pass their hearing screening and they will not need a diagnostic evaluation. Those infants are indicated in green. We do know there are infants that do not pass their hearing screening. Those are indicated in red and yellow.

We're hoping that most infants that do not pass receive a diagnostic evaluation by an audiologist. I have those shown in red. So around 36,000 eligible infants that did not pass their screening and moved on to the next stage and got a diagnoses. Again we know our system isn't perfect. We are missing some infants that don't receive the next step of services. Those infants shown in yellow are those that did not pass their hearing screening but also did not receive a diagnostic evaluation. Does anybody have any questions?

>> Have you guys considered removed the deceased babies from the denominator as they're not really eligible anymore? We're never going to hit that mark of getting 100% if we're counting them as needing it.

COREY LIPTON: Yes. So, um, we have talked about it. I think for consistency across the numbers and have them add up to 100% is kind of why we go back and forth. We do know it is a small percentage of infants that have died. We do have that on the website to one of the reasons why they do not receive screening. We do like to indicate that is a potential reason and that is out of our control. It does get a little iffy with the eligibility. For purposes of numbers and formulas having it add up to 100% makes it a little bit easier for everyone to understand and to keep it kind of consistent across the different states reporting.

>> I just have a question on consistency and definition. On the top you say diagnoses and the other two things they received diagnostic evaluation. Those are two separate things. Can you explain which one you are using?

COREY LIPTON: We are looking at that initial diagnostic evaluation for the benchmark. Going into the next stage we then focused on those diagnosed with permanent hearing loss. Apologies that we are going back and forth on those. It is that diagnostic evaluation by 3‑month of age as we're looking at as timely.

>> You can get an initial diagnoses of 3‑month of age and initial testing of 3 months of age but not be diagnosed hearing loss until later. After 3 months, right? You go to the diagnostic appointment and they're undetermined. You go back 3 months, and they diagnose you with hearing loss. Is that right?

COREY LIPTON: Yes. For those that report iEHDI data. We have that initial visit that you're indicating that maybe they don't give a final diagnoses, but they give testing. We've got options for the first completed diagnoses and then the most recent diagnoses. In our individual level data we're able to get more granular with that. For the aggregated data we really are looking for that first appointment with an audiologist.

>> This is Gina speaking. Do you have the number from eligible for screening and then did not ask the screening? Is there a national refer rate on screening?

COREY LIPTON: It is usually around 2%.

>> Thanks.

COREY LIPTON: That can vary state by state by nationally it is about 2%.

Okay. I'm going to go to our next slide. Similar to how Erika was showing by 1 month and eligible population and served and compare.

Okay.

So as a reminder the red babies did ‑‑ yellow did not pass the screening and did not receive a diagnostic evaluation. These two groups are the ones who make up those eligible babies. If you remember from our pie charts that 63,000 was who we had as the denominator. So that's all those that did not pass and were referred directly to diagnostic testing.

We've got our formula at the bottom here. Using this eligible population as our denominator we get a 3‑month benchmark of 42.7%.

For CDC's purposes doing surveillance we really want to focus on this entire eligible population. I'll show the served. Again just those infants that received services. They did not pass but they did go see an audiologist. And this is where our formulas start to really widen. Here you can see the served formula shows a result of 74.1%. Compared to our 42. And then to show both together we can see and trickling down with our numbers like we just discussed about 2% of our total birth population do not pass. As the numbers get smaller these gaps widen. The big point we want to make here is that it is not necessarily that one formula is good, and one is bad, there is utility in using both, but from our CDC public health surveillance perspective we want to look at that eligible population. That results in a national benchmark of 42.7%. Looking at the served population formula this is a good formula to look at. You can see of my kids that are getting those services, are they getting it timely?

Just want to hold if there are any other questions.

>> This is Jeff. Is one way to understand this difference is that the served population is a primarily a measure of timeliness. Did we do our diagnostic evaluation of 3 months of age looking at the entire population of kids that did get the diagnostic. Is that one way to see it more or less?

COREY LIPTON: Yes. In a sense. I think they're both measuring timeliness because of that numerator. They're both timeliness measures because of the three-month benchmark looking at those that did receive the services at 3 months but just different denominator.

>> We don't know how many are lost to follow up or lost to data.

COREY LIPTON: Correct.

>> That's what you're losing. It sounds like the eligible population you're doing both timeliness and follow up of data. I want to make clear that you heard what CDC, and this is what HERSA thinks as well. We are in lock step, and we need to think about the top eligible population and not just the served when reporting. These are different numbers. Timeliness remains important but we need to think about the lost. I know we all do. When we say 74.1%, we give the impression to the world we do not do loss to follow up. That is important. We're hoping to make it clear it is the eligible population that our EHDI programs need to think about as well. Questions.

COREY LIPTON: Thank you. That was very well said. Do you want to ‑‑

ERICKA ODOM: I just wanted to add to ‑‑ the lost follow up to documentation is critical. That's what our programs need to understand to sort of put use the data for action. If you're looking at the eligible population and you realize that number is really know you can look at your system as a whole and try to figure out where those gaps and leaks are. I think that Jeff had had a really nice slide. He may be presenting that later where you talk about the data ‑‑ flow of the system and how there are leaks at different points. It may be a hospital at your state that is not reporting timely. It may be an area in your state where you don't have a number of pediatric audiologist. So those babies aren't getting in your system in a timely way. This formula, the eligible population formula helps you to think about that. You can do with that in juxtaposition and comparison to the served formula, but we want to definitely focus on increasing those babies that are eligible that didn't receive the services.

My turn again. I got up anyway. Thank you.

So now we're going to go on to early intervention at the 6‑month time point. Just to let things settle in I want to see if there are any other questions.

>> I don't know really the best answer to this. Thinking about the 3‑month milestone and if we're reporting the first diagnoses, how are people treating, if we have a first diagnoses and it is undetermined, a lot of times that kiddo is not going to go to early intervention because the diagnoses is an undetermined loss. So then they have a second diagnostic and we end up counting the second one because they've determined that its normal or they've determined that its permanent. If they determine it is normal they're not going to be needing early intervention. If I take the first diagnoses of undetermined they're going to need EHDI and they're not going to get it because they don't know that they have permanent hearing loss. The second one was done late by, but the first one was done on time?

>> Being a parent of temporary hearing loss. A large population of our guys are temporarily fluctuating due to allergy sentence and stuff. In my findings those are my kids that are failing school and struggling because they don't have that chronic follow up unless the parents have are on top of it. Those fluctuating and temporaries are to make sure. We're running language acquisition and that also includes academics to get these kids where they need to be. I guess my question is, why are we just focusing on permanent?

ERICKA ODOM: Okay. I want to address the first question and then I can try to move on to the second question. The first question, I think can you repeat again your point. I don't want to miss it. Looking at just the first diagnoses versus if something else, if they get a final diagnoses later, right.

>> Right.

ERICKA ODOM: And that child moves back to either they have normal hearing or not.

>> Right.

ERICKA ODOM: I think we have to think about our data. It is going to be ever changing. If you take a cross‑sectional cut of your data. Meaning you get whatever information you have at that time it is what you have to report. We have to be okay with that. Because babies are going to go in and out of a system depending on what an audiologist reports. So we're not reporting these numbers as in percentages as a penalty. It just is what it is at that point in time. I think we all have to settle in on that and be okay on that. Different states are going to have different numbers based on what actions they're trying to improve in their system at that point in time. Okay.

And then to address the second question, in many terms of any data system you have to figure out some concrete definitions that you can work with. With permanent hearing loss that is one thing we know is not going to necessarily fluctuate. We look at permanent hearing loss. It might not be perfect, but it is what we have, and we can count on as a 1 or a 0. That's how I think of data. It is either there or it's not.

So permanent hearing loss is the definition we use at that time point.

>> I'm sorry. I just want to jump back to the next question. EHDI coordinators we're reporting that a child received a diagnostic testing before 3 months of age and then when we're reporting to you, the way we look at this data we're saying that he's in the eligible for early intervention but later he results he is in a normal hearing. He didn't need early intervention but still counting in the bucket that we as EHDI coordinators should have enrolled his family into. You see the disparity that we're looking at? I get that it is hard to do, and you have to take slices of time and report how it is, but it is fairly regular thing that a child receives a diagnostic test before three months of age and goes back and has a normal hearing diagnoses. It changes that bucket of eligibility and a child is ineligible and no reason to be in intervention. Really I think that is the point that Chris was trying to make. Yeah.

ERICKA ODOM: Yeah. I appreciate that. Do you have a suggestion on how to improve that? Yep. Okay. So my point still stands. Thank you very much. Thank you. Thank you. All right. Let's move on ‑‑ well. No. There you go.

>> This is Niam. I'm from Michigan. I do loss to follow up. I'm reading your timeline. We do a screen and rescreen by a month and follow the diagnostic. A lot of our babies have Medicaid and can't get them in a month for a screening. Should we refer them directly to a diagnostic and skipping the rescreen?

ERICKA ODOM: I cannot completely answer that because it is going to be based on your state rules and regulations.

>> Thank you.

ERICKA ODOM: Yeah.

>> I'm Trivy Brown. I want to emphasize on something that Ericka said. Looking at the data that CDC recommended. It is not a penalty. It is really understanding your system and where there are leaks and having a powerful measure to look at. So it is not meant to be a penalty in any way. I just want to go. It is sort of a quality improvement approach. I just wanted to make that point.

ERICKA ODOM: Thank you.

>> If I can just add to that. If you get above 75 or 80% for huge population health screening programs that's fantastic. That's way better than most public health programs. No one is thinking to get to 100%. In our life that is not how it is going to go. It is not about perfection but making sure we have numbers and count on and see better over time. Deep breath.

>> From ARSE perspective in the health and human services look at what you're asking us to meet as a target for our enroll enrollment into EI enrollment and we can't ever meet the target because we have the kids that pass away or move out of state or decline and since it is still in our denominator we have a hard time moving the needle higher because of those kids that are never going to depending on the demographic of the year we have kids that pass away between the diagnostic and early intervention. It is not possible to enroll them. It still makes our numbers look bad because they're counted in the denominator.

ERICKA ODOM: Can you tell me about the target you're referring to. Are you talking about the 1 ‑3 ‑6?

>> No. Just like what is our enrollment percentage for our CDC grant. Our benchmark. Like 80%. I feel like we're never going to reach that because we lose so many kids in the process.

ERICKA ODOM: I'm just trying to clarify what benchmark you're talking about. In our CDC NOFO I think what we've asked for in terms of improvement across the funding, the performance period, is it 30% increase from your baseline. Your baseline was based on 2018 numbers. So it is not 80% for most of you. The 30% increase was based on the baseline of the denominator that we're talking about, which most of you are in like that 30, 40, maybe 50% range. So that's my perspective, but I may not understand your perspective from reporting to higher ups. I will tell you, this presentation that we're going through and explaining the denominators, um, is something that I've written up in a letter. It is going through clearance. It is something that I'm going to share with all of the recipients in an e‑mail. It is something that you can use to share with your higher ups. But again, if you can explain to me what it is, your concern is based on what you're explaining to them and then the benchmark you're trying to reach maybe you can have a conversation about that.

Okay. But did that help a little bit? Okay. Thank you.

All right. Early intervention by 6 months. The performance measure for early intervention by 6 months is listed here.

Again, we're looking at the eligible population in our CDC recommended denominator versus the served population in the denominator. Eligible versus served. The numerators are consistent with both formulas. As you may have guessed the denominators are different. CDC includes infants eligible with intervention. All infants with hearing loss. The served population are those that received intervention and enrolled in part C or non‑part C in early intervention. In the next few slides I will demonstrate those formulas visually again with the pie charts and then the babies.

We will keep incorporating the pi chart. The eligible population for 6‑month benchmark is all infants diagnosed with hearing loss. That is about 6,518 babies. We take that 2% and then we move to diagnostic evaluation. That is about 63,000. By the time we get to early intervention enrollment, that's about 6,500 babies.

All right.

So comparing the 6‑month benchmark numbers we can take a similar approach that we had had with a 3‑month benchmark. For 6‑month our benchmark discussion we are going to start with the population of infants that receive a diagnostic evaluation. The numerator again is at your top purple. That number remains the same for eligible and served population. Most infants that go through audiologic have normal hearing screening. These are illustrated as the screen babies. There are infants that are diagnosed with permanent hearing loss, and these are shown as the red and yellow babies. Among those infants that have permanent hearing loss most are enrolled in early intervention services. These are shown in red and represent our served population of infants. We know that all of them are not going to be enrolled. These are the yellow babies. On the next slide we will breakdown those denominators again. The red babies are permanent hearing loss and enrolled in early intervention. The yellow babies were enrolled in permanent hearing loss. These two groups together make the eligible babies. Eligible for services. The CDC recommended denominator is looking at this entire eligible population. All infants that were diagnosed with permanent hearing loss. This results in a national 6‑month benchmark of 42.4%. All right.

The served denominator is looking at those infants that were enrolled in early intervention services. They are missing about 2 thousands 592 infants that don't make it to early enrollment. This is a national percentage of 70% that are enrolled at early intervention services at 6 months based on the served population.

So now to have them again side‑by‑side. By eliminating that 2,592 infants or yellow babies that were not served the numbers can look different.

42.2% of babies eligible to be enrolled in early intervention were enrolled on 6 months based on the eligible population. Whereas 70% of babies were enrolled in early intervention services based on a served population.

The JCIH guidelines state that those infants identified with hearing loss should be enrolled by early intervention before 6 months of age. We want to look at that entire population of infants who are diagnosed with permanent hearing loss.

And that ends our presentation of the different benchmarks. We've gone through 1 ‑3 ‑6 looking at the eligible and served population infants.

Now we're going to move on and transition to an example that we have of lost to follow up. Then we're going to move on to a game that hopefully helps us settle in to both definitions. Question in the back.

>> This has been really helpful. I'm Jody. I'm moderating the room and a parent and have children who have hearing loss. Permanent and following along program because of risk. That prompting me to look into a PhD program which I'm also in. I'm looking at these and thinking my son who have fit underwent into early intervention, but it doesn't mean that they showed up to actually serve him. So we had to move, and I know families from my rural area who never did move and so maybe they're in that box of people or eligible babies who entered the early intervention system but they're not appropriately being served. So my question is what are we doing to follow along those early intervention babies so those ones that enter the system. How are we tracking who is actually serving them and how often they're being served and if they're actually going ‑‑ we want all babies to thrive, right.

ERICKA ODOM: That's right.

>> Curious if you can answer that.

ERICKA ODOM: So the thing about public health and data is that it is imperfect. And what we try to do is I've heard the term sort of being counting. It is our little babies behind what we're doing. It is the 1s and 0s and we have to make definitions over time. For this system to work, the EHDI system to work, for us to get these numbers that we're reporting the coordinators, and the Public Health Departments have to do a tremendous amount of work just to get this data. So they're working with hospitals. They're working with their state vital records. They're working with audiologist in the community and they're working with Part C providers in the community. They're working with folks in the Part C Programs at the state level. They're doing all of this to create the data that you see on this slide. So they can't necessarily do everything. Right now they're just getting the numbers into the system. The quality of the serves that infants receive should be a focus of the part C program which is not really what this EHDI system does. We're just trying to get the count right, but the quality is very important. So we all have to kind of play our roles. That's kind of what we're doing right now. Jeff has some additions.

>> Thanks. All is not lost. We are working on that. I think that follows under that language acquisition question. And so in some states. I'm in Arizona. We are looking specifically at putting in place a data system that will allow us to look at the intensity of services and language outcomes. All states as a group surveillance aren't ready for that yet, but I think there are pockets that are and working towards that. I think we're going to get there all of us. It moves at a government glacial space sometimes.

>> That is a fantastic question. It is about every baby who is Deaf and Hard of Hearing acquiring language. That's what the whole program is about. As you heard Ericka say is how well is it working and how do we move forward. Right next to the systems. The EHDI Wednesday will give examples. We're doing great on 1 and 3 but six is where we have trouble. Quite the opposite. We're having trouble at 1s. We need to work on hospitals and audiologist. It is a way to move the system forward. That is one part of the answer. The part is when I was in Florida I was in charge of the early steps part C. In some states it is fairly meager and Medicaid paying for stuff that matters. For children Deaf and Hard of Hearing it is amplification or sign language and that may not happen in Part C. In most states it doesn't. To me it is a systems integration. Is part C working with Medicaid and birth records? This is one way of saying at least we have a connection with part C. We know that is important. You are right. It is not the answer to everything else. Early care and patient sites are probably more important. That's I do. We're trying to move to language acquisition and states will be able to report. As Ericka points out it is a huge amount of work to move this. We're with you all the way.

>> Hi. Durga from Virginia. I have a little bit of example to give insight on why it is so hard to collect data and like the quality of early intervention and like the practices. So in Virginia early intervention is housed within the Department of Developmental and Behavioral Health Service. That a different one than EHDI is housed with us. Due to FERPA laws we are unable to have data on early intervention and whatever announces they're conducting to be released to us. So currently we are working on developing a data sharing agreement. I'm assuming they're the ones collecting the information. What's working and actually happening with all of the early intervention programs. So I think that might be huge. That's for us at least a huge roadblock. So it is hard to gather data in that way.

ERICKA ODOM: Corey Lipton will come next, and we will come to the fun part.

COREY LIPTON: Okay. We've alluded to this as we've gone through these formulas. Looking at that eligible population there is a subset of infants that we categorize to lost of diagonal and lost to follow up. We're going to dive deeper into this.

So from the CDC definition lost to documentation and lost to follow up cases are defined to not received due to following reason. Unable to contact. Family contacted and unresponsive and unknown. Essentially we are unsure why these infants did not get the services they needed. This is why we include these babies in the denominator, and this is an area that we can target for quality improvement.

Now I'm going to touch on the two data sets collected by CDC. In our presentation we were showing you the hearing screening and follow up survey numbers from 2021. This is the HSFS. It is available on our website and collecting since 2005. It can provide us counts for the lost to documentation follow up. Because it is aggregate level data we can't dive deeper into socio demographic trends. The current agreement is to require all recipients to submit individual data's that we call EHDI. It allows us to have the socio demographic trends that we can't with HSFS data. With iEHDI we can do loss to documentation and lost to follow up further.

Now we're going to get into a case study. Hopefully we can make a little more, make this a little more interactive. We're going to play EHDI Bingo. We will pass out cards. I do apologize we don't have the fun colorful stamps. We have pins. We will get those passed around for everybody. While Ericka is doing that, what we're going to do is we have this flowchart that I'm using as the example for our case study.

So you're going to get your Bingo card. We will talk about the numerator and denominator and what your 1 ‑3 ‑6 benchmark calculations would be. Hopefully this isn't too tiny. If anybody has any questions or can't see a number please let me know.

>> I have a quick question on your definitions. There was a mention made that EHDI coordinators could get access to either the HSFS or possibly the iEHDI data. Do we have access to that to see state by state comparison?

COREY LIPTON: With the current cooperative agreement our data user agreement do not let us publish the state by state information with the individual data. It might be something that we can move towards in the future. For now the iEHDI is not available. The HSFS is available in the website. I don't have the URL. I can look it up and we can chat after so you can have it.

>> To clarify if states want to access their individual data they can reach out to CDC, and we can give you the data that you submitted at that time. It is available to states, but CDC agreed not to publish that data. First it was our first time collecting that data from you. We didn't know the quality and how different it might be from HSFS.

>> A couple of times you mentioned demographics and lost to follow up. Do you have any demographic numbers to follow up the result.

>> YOU: (Speaking).

ERICKA ODOM: We do have the website in HSFS. Maternal and race ethnicity. Some age. It is just a few variables that we have for HSFS. That is on the website. By 1 ‑3 ‑3 and socio demographic. We do collect a little bit more on the iEHDI data sets. We are doing analysis. Again we can only publish national level. We have taken the national data level and doing analysis. Corey is looking at lost to follow up and disparities. It takes a time like it takes time to do publications. She is working hard on one. She got a special program with CDC and looking at health disparities. We have a presentation this week by Kelly Dundan. She will be looking at completeness of data and breaking that out as sociodemographic level. The data you have to play with it, and you can do it at your state level too.

COREY LIPTON: For Kelly's presentation it is demystifying. I believe it is tomorrow. Oh. It is tomorrow from 3:10 to 3:35.

ERICKA ODOM: Unless it changed. This presentation got changed. If you see a different one in the app, the app seems to be what is accurate. It is called Demystifying iEHDI. That is the completeness of data by sociodemographic characteristics. Okay.

Okay

COREY LIPTON: We will start to play Bingo. If you get Bingo yell out Bingo.

For our first question. This is going to be number the numerators column. What numerator would you use to look at children who don't have a clear reason for missing their hearing screening?

What numerator would you use to look at children who don't have a clear reason for missing their hearing screening? For that one it would be the screening lost to documentation and follow up for 500.

That distinction is they don't have a clear reason for missing it. We document reasons for why children were not screened. A lot of them are known reasons. Like we mentioned family decline, infant death. Moving out of the jurisdiction. Yes. Lost to follow up is our population where it is ultimately unknown why it wasn't received. It should be, and I'm sorry. I can probably put, if I can find the mouse. Oh. This number. About 500 there. Okay.

Going to the denominators. What denominator would you use to look at the timeliness of the served population at early intervention enrollment? So this is for the denominator. So it would be this total enrolled into Part C.

So when we think about our served population it is those children that receive the services. So if we wanted to see how timely they served population is getting those services we would look there.

>> Do some of us not have it in a row?

COREY LIPTON: Yes. Yes.

ERICKA ODOM: Your cards aren't going to be the same.

COREY LIPTON: It is Bingo. It is spread out. If there are any Excel nerds out there and see how I made these cards it is a fun project that took a little longer than I thought. I tried to spread it out. Yes, you might not have it. Under 1 ‑3 ‑6 measures. What is the value of our one-mark benchmark? I tried to put it there, so you don't have to do math. You can find the numerator and denominator. Just as we're looking ‑‑ I keep losing the mouse here.

So our 1-month numerator is going to be this screen by 1 month here. And does anybody want to shout out what the denominator for that would be? Yes. The 50,000. So that gets a total of 95%. Okay. This might help get a couple of spaces on your card. Under the lost to documentation and follow up, what is a reason that a child can be categorized as lost to documentation or lost to follow up? We have those three different reasons. If you have any of those you can check them off. And if we remember it is ultimately unknown. That would be unknown, unable to contact, and family contacted but unresponsive.

>> That again.

COREY LIPTON: This is one where you can put all three. Under loss to follow up, what are the reasons for a child being categorized as lost to follow up. Those were ultimately unknown reasons. Unable to contact, family contacted but unresponsive and unknown.

Okay. Going to the iEHDI HSFS column. What does the i in iEHDI stand for?

>> Individual.

COREY LIPTON: Individual. Yes.

And we will do another iEHDI HSFS question. What month is the preliminary iEHDI file due? The first time you submit your cohort to CDC? If anybody remembers it was just a few months ago. November is that first submission.

What? Okay. We will jump back into the 1 ‑3 ‑6 measures. The middle column. What is the value of the 3‑month benchmark? Yes. Based on that. If anybody knows it feel free to shout it out. This will be our numerator. That 582. And then our denominator is that total not passed. That results in 60%.

Okay. And going to the numerator's column. What numerator would you use to look at children who met the 6‑month benchmark. It is down here at the bottom. I'm sorry this is probably very tiny for those of you in the back. If we wanted to look at the numerator for the 6‑month benchmark it would be those that are enrolled by 6 months of age. That is 50 down there. Going to denominators. What denominator would you use to calculate the 1-month benchmark? Does anybody want to answer? So for the denominator we would want to look at total births at the top for that one‑month. Okay.

We will go back to our 1 ‑3 ‑6 measures. What is the value of the 6‑month benchmark. So we just had a question about the numerator at 6 months. So we know it is this 50. So combine that with our denominator at the 6‑month benchmark. Does anybody want to shout out the denominator? Yeah. 102. Nice. That results in 49%. Nobody has Bingo yet? Man. I mixed those up really good on Excel. Okay. Let's go to iEHDI and HSFS then at 5th column.

What month was the 2021 HSFS uploaded to CDC's website?

For a spoiler it was January. Yeah.

>> That was a tongue and cheek question because we did it late this year and everybody was asking.

COREY LIPTON: Yes. It is up now we promise. Okay. I think ‑‑ let's see. This should help people get Bingo.

What is a reason for missing the required screening diagnoses EI enrollment. Any of those throughout the EHDI stages that is not lost to follow up or lost to documentation. Any of those known reasons that you would not categorize for lost to follow up or lost to documentation?

Is anybody close to Bingo? Man. I made those too good. Okay. Yep. And everything else. Everything that is not lost to follow up or lost to documentation. You can feel free to check off all of the other reasons in that column. Maybe that should help with Bingo.

>> Question. Why do you write home birth?

COREY LIPTON: Home birth can be a reason for a child to not receive screening. That's something that we document in the HSFS. Okay.

We will go over to ‑‑ let's look at iEHDI HSFS again.

What month is the final iEHDI data file due? So the preliminary one is due in November when you submit the second round of iEHDI to CDC when is it due?

>> May.

COREY LIPTON: May. Yep.

I'll just say on this column, what portal should the iEHDI data be submitted to? HSFS is red cap. Sams. Yes. We will go ahead and go with that second one. Where is HSFS submitted to? Yeah. Red cap. You do? Yeah. I was getting nervous about those cards. Yeah.

All right.

ERICKA ODOM: We have a prize. I don't have it with me. It is in route. We have a prize for you. Come find me.

COREY LIPTON: Okay. Thank you all for your participation and EHDI Bingo.

Now we're going to have more of an open discussion. So looking at these numbers here, we're going to focus in on the population that was lost to documentation and follow up at the 3‑month benchmark. So they did not receive their diagnoses, but they did not pass their hearing screening. So I've made up some dummy data for this population and these data are based on variables. We have an iEHDI. We have mother's primary method of payment up in this top left corner here. For those of you that submit iEHDI data you know there are variables that are required and others that are not required. Mother's primary method of payment is not required but it does give us insight on socioeconomic status. For other states there is a big bucket of unknown. Over the top right we have mother's race. In the bottom left‑hand corner mother's education level. And then finally mother's age group in the bottom right corner.

So if this was your state, and I can give you a few minutes to mull over it and discuss amongst the tables if you find that is more helpful. Using this data, what problematic efforts would you use to target this population?

>> So the screen colors look similar in the little squares.

COREY LIPTON: Oh, no. Okay.

>> Maybe it is just me.

COREY LIPTON: It did come out small. What if we talk about each variable individually and I will read off those.

For mother's largest portion of payment you can see that 44% is other. So there is a bucket for Other in that variable that it didn't fall under private insurance, Medicaid, or self‑pay. 24% is unknown. 19% is our Medicaid population. Oh, wait. I'm so sorry. I might have switched these. It is hard for me to see on this too. Apologies. 24% is private insurance. That's dark blue in the corner. Yeah. Yeah. Apologies. It was hard for me to see on this too. 24% is our private insurance population. 19% is our Medicaid. Self‑pay is 2%. Other is 11%. And then Unknown is that 44%. Apologies. It goes like a clock. Um, so this is what I put Unknown. This should of triggered me that I was looking at the wrong category. I put unknown in 44% because I'm doing an analysis in documentation and follow up and I'm usually seeing this variable is missing around 40% of the time. Again, it is not required to be reported under this current cooperative agreement, but it is an important variable you can look at to help target problematic efforts.

For the point that I wanted to make about this, because it is mostly unknown, it is kind of hard to use that variable to help you understand that target population. It does let you know from a data quality improvement perspective that that is a variable that you might want to go after collect anymore.

So now if we move over to mother's race. I promise I will get this right this time. We got a population that is 41% white, 26% black, 18% Asian, 6% Native Hawaiian or Pacific Islander or Alaskan Native.

>> I would want to note the lost to follow up and lost to documentation for these tables before I make a decision on who I want to target. So does that the idea or are we saying this is our biggest population, why wouldn't we target them. Do you know what I mean?

COREY LIPTON: This is looking at based on the case study honing in on the follow up and documentation population and diagnoses. That is kind of our basis here. No. To your point I'm just showing you an example of data.

>> I know. Thank you.

COREY LIPTON: That was a good point though. You want to look at rates. Hey, is this really high? Should we target this? That is a good way to look at it from the rates perspective. I think that is a good starting place to know if that is an area of improvement for your area.

>> What I would want to know is lost to follow up rate, is that reflective of your states demographics overall? And where is the disparity. The second thing I would want to consider is who is doing that follow up and if there is a parity or disparity.

COREY LIPTON: This is great, but if you don't know your underlying population how do you know this is different. These are just pieces of the puzzle and trying to get more thinking on. Okay. If I was given this data what approaches would I take. You would need to look at the full denominator. So we will go to education level. We've got 41% that are less than high school. 44% high school graduate. 12% some college and only 3% that are college graduate or more. So looking at this what insights can you pull for this population?

>> You better look at the reading level for all your materials for one thing.

COREY LIPTON: Yes. Yes. Good point. Yes. As we're alluding to this population having less than high school and some college and high school graduate, that's making up the most of your population. So problematic efforts. Looking at reading level is really good. Now, if you see this in conjunction with the age group though, going across it is 3% that are less than 15, 36% between 15 and 20, 41% between 20 and 24; 12% in the 35 to 40‑bucket. 7%, 35 to 50 and a small 1% for greater than 50. If you see this age group does that help you gain anymore insights with your education level?

>> I was thinking you should think about electronic access for websites of that kind of demographics if you are providing that information. It might be better than paper.

COREY LIPTON: That's a good point with the younger population.

>> I can't help but think that there could also be a real place for FBO's in many this. Parents who have been there and speak the parent language to help in both of those ‑‑ yeah.

>> So this conversation makes me so excited, and I can't sit down and not make a comment. This is like the exact conversation. This is why you use your data. It is telling you so much about what you do with your program and why. This is just looking at made up data. Lost to follow up at 3 months. It is telling you so much about how you push your program forward. Who do you need to speak to? These mommies of these babies are young. Maybe social media is the place we need to share some information with them. We don't have a lot of information about their primary method of payment. So we might need to work on that because they might be lower income, or they could be higher income. We don't know. And then you look at your race ethnicity and you decide am I meeting the population where they are? Are my materials culturally sensitive? Is this reflective of the population across my entire state. Am I potentially missing babies or just my population of infants who are at 3 months what's happening? Getting diagnosed. Are we missing somebody that is diagnosed? This is what it looks like for us. This tells us so much and it is important to use our data for those purposes. I could not say that. I'm sorry. Thanks.

COREY LIPTON: Thank you for all your comments. Those are great ways to think about it and looking problematically. The only other paint I wanted to make is how you can use the data together. If you just looked at education level you would think this is not as an educated population, but looking at that in conjunction with the age group it makes more sense that this is a younger age group. So maybe they just haven't had time to get that next level of education. So you want to look at all different aspects of your data so you can draw insights. You definitely want to pull in what your population is, you know, your birth population or then moving down into diagnoses and looking down into population of those that are not passing their hearing screening. Especially in this instance and looking at lost to follow up and documentation and diagnoses. If this population is different, then your denominator you got ways to target them. Again sorry this was so tiny. So that was it for the interactive portion. We had Bingo and a case study to get the wheels turning of how you could use your data.

Our key takeaways. Again our most important point. These are not just data points. These are babies. We just need to keep that in mind as we look through our data. Our different denominators yield different metrics. We can look at our eligible population, which is what the CDC recommendation for the 1 ‑3 ‑6 benchmark. Related to that all formulas discussed provide important information. You can definitely use both that eligible and those served denominators to give you insights on your program.

Being so excited iEHDI data we know you have worked hard and a difficult journey to get that individual level data. It can be powerful for your programs and improvement and identifying those infants that are not receiving those services. Understanding that loss to documentation and follow up population can help improve and strengthen follow up efforts.

That was our presentation. I know we still have time in the room here. If anybody does have any questions we can take more questions at this time. Thank you, all, for coming to our session.

>> I was just basically when I send you guys this report I for some reason if I open it corrupts the data for like how we submit it through SAMS. I was wondering are you guys as a CDC do you have plans to work with the EHDI programs and like identify things? I'm just wondering in general what are your plans and how are you planning to work with states with this data.

ERICKA ODOM: We have a number of ways that we work with states. Primarily through what we call technical assistance. So we are on those data committee calls. We're on those outcome committee calls, and we have, what do we call it? Our office hours where we have open lines of communication. We provide all EHDI coordinators and data teams to come to those calls and we talk about data most of the time. We talk about I am very open to understanding like why is it hard to use your data? Why is it hard to get to understanding what your iEHDI data looks like. We provide technical assistance in a variety of ways. It could be through those office hours, or we have quarterly Webinars. The next Webinar will be held, I don't know off the top of my head.

COREY LIPTON: We're doing a data focused Webinar March 28th, next week. If I know what today's data is. We're going to show you an overview of the 2022 birth cohort for iEHDI. The data that was submitted in November. Just to give you an overview of what the data looks like. To piggyback off of Ericka if you are interested in data analysis and want help, we're more than willing to collaborate on papers or something programmatically. The data team is myself and Laura and we would love to look at data if there are any data if you feel like you need additional support.

ERICKA ODOM: I do appreciate them and then willingness and ability to help. I also want to note that we have with the supplemental to the current NOFO we asked states who were interested to apply for supplement funds for this coming year. The focus would be on data analysis. Looking at 1 ‑3 ‑6 benchmarks and sociodemographic instances. We're providing help in a variety of ways. We can have that help. In a broad scale we have like many different avenues where we are providing to you. We also, on the scale of things we have to look at the data that you send and provide national numbers, right. That's part of our role. So we provide numbers to HERSA for the congressional justification. Those same 1 ‑3 ‑6 benchmarks we publish on the website we provide to HERSA. They provide NIH with the numbers. We're calculating those numbers and sending those to healthy people to look at national progress across 1 ‑3 ‑6. What other ways are we using our data? We're using our data to do many presentations at the EHDI conference, which eventually turn into manuscripts and take time. I have a list. If you come to the EHDI 101 session you will see me post a list of conferences. CDC teams is there. I can talk about them. Told is the baby flow presentation. This is using your data. The EHDI 101, again I will just be sharing with you what the data is. I'll go over what is FS and what is iEHDI and what is the presentations and going on in the EHDI conference. Most of them will be held on Monday. The different titles, and I'm going to read them off as slowly as I can. 10:05 on Monday we have consideration and documenting language outcomes for infants that identify as Deaf and Hard of Hearing. That is look comparison and results and aggregated and individual level data from 35 states. That is going to be on Monday at 12:00 P.M. That is a poster. That is the difference between iEHDI and HSFS what we see so far with the 2021 data. Again 12:00 P.M. Monday we have the cross-agency collaboration and support of HERSA and CDC EHDI funded programs. That is our logic model. That will be in a poster format. I encourage you to go look at that poster. Again at 1:55 we have improving diagnostic Audiology Reporting Using an Intelligent Document Processing Solution. That is looking at special sort of analysis ‑‑ not analysis. Special funding that we did to look at machine learning and Ai to really try and pull data out of audiology reports. So we're trying to figure out if there is ways we can support moving the technology forward and making it easier to get information out of that audiology reports into the data systems. So that is a special program that we did with the public health and informatics institute in Atlanta. 2:25 audio metrics audio screening hearing. That will be led by Kelly Dundin. She is looking at what happens if you move some babies in different buckets around if they don't pass their screening hearing. Once we get additional information about those babies. Then at 3:10 on Monday we have the demystifying iEHDI again. That is okay looking at the completeness of the i EHDI set and sociodemographic. We're a busy team. We try to submit and share back what we're learning. All of those we hope will be developed into manuscripts at some point. So be looking at for those in the next year or two. It takes a good while to get publications together. I think we all know that. On Tuesday we have two presentations. Language growth over time and young children with bilateral and hearing differences. That is using the Audicy data. Then I will be presenting at ‑‑ no. That is Wednesday. What is this one? I don't know this one. I think that is a presentation and not our exact presentation. My presentation on Wednesday with, I would not have got that done without the support of Kelly Dundin. I will say that on Wednesday also. Understanding and using data to inform. We have lots of presentations. Lots of data to share. We will continue to share data whether it be at our ‑‑ what's the name of our calls. Office hours and Webinars. The office hours are monthly. The Webinars are quarterly. I encourage you all to attend and have your data folks and data analyst to attend. We like data. We know that the EHDI data is not easy. We would like to talk about it and really learn from each other because we learn from you all and we learn to improve the program by having the open lines of communication. Thank you so much. I really am glad that you all joined. I'm not going to end.

>> I have a quick questions. I'm Melaney from Georgia. EHDI is in our office. I have not been intimately involved with the data uploads. Are we about to switch from going reporting served population to eligible population data? Is that how we're ‑‑

ERICKA ODOM: You've always been reporting eligible population to CDC. We just want to make it very clear why we ask for eligible population. I think there has been over time some confusion or blending of what those different denominators mean. For public health services we want to look at all eligible babies. We're just making it clear what it is we're asking for in terms of what we're reporting. Also you will see own the next year or so. CDC's web pages are being updated. We're being asked to have a very clear communication objective. If we're going to do that we're going to have to share with you what we define as the population that we're looking at for CDC.

>> Okay. That is really helpful. Also we have an agency collaboration and the way we report our data is not ineligible. It is good for me to now know we need to be reporting probably in the same way that you are defining it as eligible.

COREY LIPTON: I'll just say HERSA supports this approach. I want to be clear in many past years on the website both denominators were reported. Now it is kind of being streamlined. There is one denominator being reported. I just wanted to make that clear. HERSA definitely supports this approach. Again, there is value in both denominators.

>> One of the things I would ask you to consider is putting more trend data in there. State specific trend data because I do it. It is a lot of work. It is nice if they automated that on each state.

ERICKA ODOM: I'm on the same page. It takes time and effort. That is something that Corey has been working on. This project is secondary right now. We do want to start ‑‑ we have this grand idea about how we're going to take all this data that we have and display it in a way that is interactive and look at trends by states and sociodemographic. We're hoping that one day in the future we can develop something that you're talking about.

>> I'm Gayle McDonald. I report the data to our EHDI Advisory Committee. I don't do any of the reporting it to CDC and my question is about eligible. I kind of thought you were saying that we tell you who our eligible babies were, or do you tell us what you consider eligible? The reason I ask is the advisory committee, every quarter when I do the screen by three months they're like well, we have more and more extreme preemies that are not getting screened because of that. Because we're a small state that really changes our screen by 3‑month data. So what do you guys define eligible or is that something that Ellen and Liza are figuring out when we report to you?

ERICKA ODOM: Your question is interesting. I don't know exactly how to answer it. Eligible has been defined in the data set. We're just giving a label to it right now. It has been distinguished over time. We just want to make it very clear what CDC is asking for. So you've been calculating both of those denominators. When you send us the data we have been presenting it to you. If you go to the CDC 2022 data you will look at 3 months and you are looking at diagnosed by 3 months. You will see two columns at the very end. I don't know if we have Wi‑Fi here. You will see two columns at the very end. It won't be labeled as eligible versus served but you will see that these numbers look very different. Sometimes in the eligible population column it will look pretty low. It will look around 40%. And then you will look at your state and you will look down the served population. Again, it won't be labeled that way, but these are the numbers. It is based on the 1s and 0s remember, that is the served population. That will be maybe what you're used to seeing and hearing. It will be around that 70%. So that is the 2020 tables. 2020 tables on the website. If you then look at the 2021 tables on the website you will see that the numbers that you're used to seeing with the higher 70% at 3 months is no longer there. That's because we're moving towards streamline very focused message of what the eligible population is.

>> Actually my question is exactly very similar about how a baby that is predetermine flows through the system. We have more and more preterm babies who can't be tested. It sounds like eligible is just like, they would always be eligible for 1 ‑3 ‑6 even though they can't be tested. Would that be correct? Would they always be in a eligible group? If you have a 22 weaker they're not tested but are they in the eligible but not screened group?

ERICKA ODOM: Yes. Eligible but not screened. Eligible is a label that is specific to the data points. So it is not about critically eligible, it is about the population of infants. We have to think about it from are a public health population health perspective.

>> Basically it is the births. Preterm.

COREY LIPTON: Preterm are eligible but not screened.

ERICKA ODOM: Eligible but not moved in the health system.

>> Have you ever thought about taking that population ‑‑ or looking at that population separately? We talk about a lot of things, but because to do QI work around premises you would have to sort of pull that population out and look at it as a subpopulation.

ERICKA ODOM: I think that is a great scientific question that you can answer with the data, but when we're talking about like the public health framework and thinking about quality improvement and capturing babies we have to let them stay in the buckets at the time that we're pulling the data. As opposed to thinking about how it might change over time for that infant.

>> I was around when the original CDC data collection for the HSFS was being developed. We had months and months of arguments about some of those. I think that what we came to was that you have to have that high‑level consistency across all of the states but that doesn't mean that the data you're talking about makes a difference of QI efforts. To make sense of it in your state you have to make that deep dive and don't have to look at the babies that are deceased. Even though that is in the high‑level stuff you can impact these kids. You still have to do the deeper dive into the data individually. It is not that you're losing that it is just that you're using it within your own state and not a national measure.

COREY LIPTON: We have five minutes.

ERICKA ODOM: We can give you 5 minutes back of your time. Thank you, everyone. It is a great session. Thank you for your interest.

[End of Session]