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Or, if you think of people who aren't attending live with us, whom you think might benefit from the content of today presentation, You can direct them to infanthearing.org, where they can view this at any time.

and the lovely part about that is that you can start and stop that video, if you want to study something that's on a particular slide, or take notes from it.

So keep in mind that... we are going to be recording today's webinar.

And the potential benefits that that provides.

We'll be starting electronic voice: Recording in progress.

>> DR. EISERMAN:

We'll be starting shortly here.

People are signing on a fair --

in at a fairly rapid pace right now, so let's give everybody a chance to transition from what they were doing a few minutes ago, to being present with us here.

(A pause), .

>> DR. EISERMAN: To our presenters, if you want to turn on your videos, we'll -- get ready to start here in a minute.

Gunnar, are we going to have them pinned as well?

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>> GUNNAR THURMAN: Yes, I'll take care of spotlighting the presenters.

>> DR. EISERMAN: Okay.

(Pause), So if I could ask our two presenters to turn on your videos, that would be great.

There we go.

I see you, Carlie.

And Emma, excellent!

Gunnar, if you want to turn me on for just a moment, you can.

Oh, I should put my video on, though, huh?

Okay.

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There we go.

.

Well, I want to welcome everybody to today's webinar entitled "Diving into State Data: How the Deafblind Child Count Data Can Help You", My name is William Eiserman, and I am the Associate Director of the National Center for Hearing Assessment and Management.

Known as NCHAM.

At Utah State University NCHAM serves as the National Technical Resource Center for EHDI, the EHDI, NTRC, funded by HRSA, To support a wide number of stakeholders in -- and around --

the EHDI System.

-- and, as a part of that, we offer webinars like this on a fairly regular basis.

I want to give a shoutout to our Interpreters, and our Captioner today, To our background technical support folks, For helping us make this webinar as accessible as possible.

So thank you.

To those of you who are playing those roles today.

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>> (After a pause), DR.

EISERMAN: My -- from a perspective of logistics, know that today's webinar is being recorded.

And what that means, is, in the next couple of days, you can access the video recording of this webinar on our Web site, which is infanthearing.org.

So keep that in mind, if there is a particular... slide or comment that you want to come back and review again.

Or if, as a part of your experience today, you think of folks that would benefit from today's webinar, who aren't attending live.

so, you can always refer them back to infanthearing.org.

On our landing page, you'll find a list of webinars and how to access the library of all of those, that have been recorded in the past.

So, keep that in mind.

(After a pause).

>> DR. EISERMAN: (Continuing), this is a coffee break webinar, so it's going to be time-limited.

Our -- our speakers today, are going to speak for about 15 minutes, and then we're going to open up the Q&A field for you to make comments, or questions to -- to have our Presenters respond to and we'll do that and we'll let you know, when to -- to submit your questions.

Hold them until you are invited to do so.

We're not going to monitor those until it's time.

And -- I think that's everything by way of logistics.

So --

Our webinar today is looking at...

Is being provided by folks from the National Deafblind Child Count, to highlight etiologies and causes of DeafBlindness such as CHARGE syndrome, complications due to prematurity, post natal complications Usher Syndrome, congenital CMV and Down Syndrome, they're going to explore trends nationally TOEFSh last three years, discuss differences between birth to 3, and 6 to 21, populations in terms of etiologies and identification, And share resources specific to the different etiologies that may help inform, your work.

Our presenters, are Emma Fricke -- sorry Emma, and Carlie Rhoads -- Carlie Rhoads, boy, sorry for that.

I'll let them each give you a little bit more details about the roles that they play, so without further delay,

I will -- introduce Emma and Carlie.

Thank you, (concludes remarks).

>> EMMA FRICKE: Thank you so much, good morning, everyone, it is a pleasure to be with you-all today for this coffee chat.

Emma Fricke, M.S. Ed.:

Understanding data trends is a critical part in the identification and referral efforts for infants and toddlers, who are DeafBlind.

Today, I am so happy, that Carlie is here, to share a snapshot of common etiologies and causes; and the trends we've seen over the last three years.

So this will be a short sort of snapshot coffee chat, and then, we will have a slightly longer presentation, at the EHDI conference.

Many infants who are DeafBlind, who are -- who are identified early, have been identified through the Newborn Hearing Screening and we believe there is immense opportunity in the partnership we have, To develop with all of you, to increase our understanding of each other's data; priorities; and needs. So, without further ado, I'll hand this over to Carlie, and, we really look forward to having a fruitful -- fruitful discussion following Carlie's presentation.

>> Carlie Rhoads, PhD:

Hello everyone!

My name is Carlie Rhoads.

And -- I basically, get to have this awesome opportunity to talk to all of you today because I am a great big, data and numbers nerd.

I am, the data and evaluation manager for the National Center on Deaf-Blindness, and one of the big tasks I'm in charge of is basically, managing the national database that we have that counts all of our children with DeafBlindness, and this is from birth to age 21.

Although some states do provide services past the age of 21; so, like, Michigan for example -- serves students until age 25.

So, Michigan reports their students until the age of 25.

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>> DR. RHOADS: So, there is a whole lot of information, and data surrounding our database; and I'm just giving you guys, like, a little taste today about what exactly is our database; what kind of information can you find there?

And then, I have some little graphics to share with you, to look at some of the trends, specifically, for younger kiddos.

As well as a little bit of a comparison between what is going on birth-3, as opposed to our 6-21 years kiddos.

And all that really great stuff, so I'm just going to go ahead and dive in because I have a lot to say, and not a lot of time to say it.

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>> DR. RHOADS: (After a pause), there we go (as slide advances), all right, just to reiterate what our

purpose is today, we're going to be highlighting some common etiologies and causes of DeafBlindness, we're going to be looking at specific trends of top etiologies that we typically see with the students that are reported, for the Child count.

We're going to look -- at the trends nationally over the last three years, for -- birth-3.

As well as a little glimpse at 6-21.

Although our main focus, will be birth to three.

We'll discuss some of the differences, that we're seeing in the trends, of birth-3, versus 6-21 in etiologies and identification.

And then, also talk about some resources, specific to different etiologies, that may help inform your work.

(Slide advances).

>> DR. RHOADS: So what exactly is this Child Count?

And, I figure we might be coming from a place where we don't know, exactly what this is. You know, like, what is this database?

And I'm sure some of you may have never heard of it before.

This is something that started back in, 1986, so, this has been around for about 37, 38 years, at this point.

And, this is a national Child Count of children and youth, who are DeafBlind; and it collects, information on this population of children that have been identified with DeafBlindness, in the United States, and some U.S. territories, so, like, -- the Pacific Basin and the U.S.

Virgin Islands are included in this.

And it's about -- birth through age 21.

Again, with some of those states, going past the age of 21, which are rare cases.

And then -- with the onset of --

the Pandemic, we had some kids that were given special dispensations to stay longer to receive services; so we have some interesting numbers in the last couple of years with some older kids staying until age 22, 23, but we'll start to see that drop-off as the years continue.

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>> DR. RHOADS: (Continuing), we collect a ton of -- um -- uh data within this database.

And this includes both state and national information.

We have things, including population demographics, this includes age of the students, race, ethnicity -- gender --

Where they're living; we have an optional -- um... language spoken at home category.

We also collect information about the type and severity of both vision and hearing loss.

The cause and etiology of the DeafBlindness; if there's a presence of additional disabilities.

Education setting, living setting.

We collect -- part B and Part C information, so, you know, -- what types of services they're receiving.

Where, like, what -- what --

where in the school they're receiving those services.

If -- what types of assessments they're getting for standardized assessments, like, pretty much almost anything you can think of, that's -- you might be interested in, I'm pretty convinced our database would have that information available.

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>> DR. RHOADS: (Next slide), so since we are talking about the Child Count, I did want to just show you guys where this is on our Web site, take you on just, like, a little, quick Web site tour.

Of... this... so I'm going to exit out of my PowerPoint.

And bring up -- this Web site, .

>> DR. EISERMAN: You got it, perfect.

>> DR. RHOADS: National PD.org,/info-center/national-count.

And if you ever are just on our main Web Page you would go to the info center tab here at the top and click on national Child Count and that brings you to our main page for the National Child Count, you'll see my smiling face there on the page so if you need to contact me, my e-mail address is there.

(Scrolling), and this gives a little bit of an overview of, like, what exactly -- a little more in-depth about what the National Child Count is; Some little quick links here on the side for our Data Center.

We've got, like, a really great in-depth -- uh -- paper, about students with significant cognitive disabilities.

And dual sensory loss that we partnered with the ATLAS folks about, so we have lots of great information on this Web Page.

(After a pause), if you scroll just a little further down...

this is where you can access all of our Reports, and this goes all the way back to 2004.

Up to present.

We did just publish, the Report for 2022.

I -- I don't see it up here yet, but that is available.

So we have that ready to go.

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>> DR. RHOADS: And we have both HTML and PDF versions going back to 2017.

(Scrolling), and --

Everything about the Report is there.

The HTML version has, like, different categories and you can zip around in the different tables and different sections of the report that way, or you can download the PDF version, and look the report as a whole, all at once.

(A pause), so I just wanted to show that really quickly.

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>> Let's see if I can remember how to bring up --

My --....

>> DR. RHOADS: All right, I think we're good to go, yes, perfect!

Wonderful (chuckling) you would think by now I would be a little -- more versed with Zoom but sometimes it's a little bit of a learning curve, all right, so the first thing I wanted us to look at were some trends from birth to age 3.

Just over the the last three years, like, looking at what's been going on with our numbers, what kinds of things are we seeing?

And those sorts of things.

And I do want to point out that when you take the totality of the kids that are identified birth to age 3, and you're comparing them, from, like, 6-21, which, you know, are the part B, older students, There's a pretty huge gap, in how many kids we're identifying and I have a graphic later to show, specifically, about that.

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>> DR. RHOADS: Something else to keep in mind, too, is -- on average -- every year -- for the Child Count, we are identifying -- in the ballpark of about 10,000 kids, I think for the most recent year, 2022 - - we were in the -- upper 9,000 range.

So on average, you know, -- kids with DeafBlindness -- this is, like, a rule of thumb: It occurs -- it's a low-incidence disability.

It's occurring in about 1 in every 10,000 kiddos and we are -- Finding about 10,000 kids, every year, with our Child Count.

It's not to say we're finding every single kid under the sun, because, as we know, there is all kinds of barriers to identifying these kids.

But I will say, that we have a huge difference in the numbers that we report on our Child Count, as opposed to, what gets reported with OCIP.

They receive their information through IDEA and have way way way lower numbers, than we do.

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>> DR. RHOADS: (Continuing), this is partially due to issues, such as: 1), kids with DeafBlindness just being labeled as having multiple disabilities on their IEPs.

Or, school districts not counting all of the (2), eligibility categories, so DeafBlindness isn't being counted.

There's lots of different issues for why that is happening.

But, I like to think that our numbers are more accurate.

We receive our information directly from state DeafBlind Projects, and -- you know, --.

>> DR. RHOADS: Numbers are not perfect. You know, they come from every single state and every state handles their data differently.

And there's always room for improvement.

But I think our numbers are closer to accurate, than what OCIP currently has.

So looking at this particular graphic on this -- on this screen, so -- for, like, top 6 etiologies --

Typically, tend to be CHARGE syndrome, CMV, usher syndrome, Down Syndrome, and then --

DeafBlindness that results from complications of prematurity, and then there's also category of post

natal or noncongenital.

So for the purposes of looking at birth to three, I did these six for each age, so we could kind of see, like, if there's any differences between the ages; so -- if they're under the age of 1-year-old -- this is -- these are our trends from 2020, 2021, and 22.

And something that I -- want everyone to keep in mind is that, of course, 2020, how could anyone forget that was the year the pandemic happened; and, because, that was such a rough year -- you know, the world shut down.

It was really hard to get numbers, And, to find kids to get identification -- we typically saw a bit of a dip, in numbers that year.

So, for a lot of these trends you'll see, then in 2021 --

You -- we see a really big spike in numbers, because, compared to what happened in 2020, when the world was shut down, we're suddenly finding a whole bunch of kids.

That tends to even -- out a bit, in 2022, but, the numbers do generally tend to still be higher than they were in 2020; so -- numbers have been kind of up and down in the last few years.

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>> DR. RHOADS: I think that's something really important to keep in mind.

But we are seeing some stabilization over time.

>> Carlie Rhoads, PhD: Ideally in a perfect world, we would see our numbers continuing to increase, you know, as we get better at identifying kids, as we improve with, you know, our identification processes.

But, always room for improvement, of course!

So....

>> Carlie Rhoads, PhD:

Typically in terms of syndromes, our top syndrome is almost always CHARGE syndrome.

And you'll see, that -- it is definitely the case, for kids under the age of one year, and they had the biggest jump, in '21, and then they eased back down in '22.

The next -- most common one -- was, post natal noncongenital.

Then CMV.

Then complications of prematurity, then Usher Syndrome and then what's interesting on this graph is Down Syndrome actually went down, in numbers, in 2021, and, I'm not exactly sure why that is.

I think it's definitely worth looking into, at some point, but that is something to note, and something you'll see on some of the other graphs that for some reason Down Syndrome took a big spike down in 2021.

As opposed to these other syndromes.

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>> DR. RHOADS: (After a pause) looking at our age 1:

Basically typically, the -- very similar to our kiddos that were under the age of 1.

We do see a sharp increase, in CHARGE syndrome.

From 2020 to 2022.

And, again, -- but for most of the others, we're seeing, you know, --

An increase, from 20 to 21 and then back down a bit in '22, the only exception here, being, again, Down Syndrome, which --

is steadily going down for kids that are age 1.

(A pause), For age 2 -- we, actually, as a bit of a change here, we see a decrease in CHARGE syndrome over time.

Although, that seems to be leveling out as well.

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>> DR. RHOADS: And -- (a pause), Usher Syndrome also went down, in '21 for kids that were age 2; so, just interesting trends to note.

And, if you'll note on the side, too, the numbers, again, are pretty small, when we're talking about, you know, -- the entire country of the United States.

So very, very small numbers.

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And then age 3:

This is perhaps, the most interesting that -- these numbers, are a little bit larger in comparison to the younger kiddos.

But... not seeing a lot of (gesturing) changes over the years, With this age group.

So just -- just very small changes for these kids.

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>> Carlie Rhoads, PhD:

(Continuing).

So then, I just wanted to do a comparison of the total number of identified kids, from birth to age 3.

Over the last three years.

So from 2020 to '21 to '22.

You'll see, with the kids under age 1, we have what we would typically expect: That from 20 to 21, there's a little bit of an increase, and in 22 a little bit of a decrease as the numbers start to stabilize but still higher than the numbers in 2020.

For kids -- um -- in the age 1 category:

We see, actually, a steady overall increase, from 20 to 21, and to 22.

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>> Dr. Rhoads: Then for age 2, we see, again, -- what we would typically expect, going, (gesturing) down in 21 and then back up in 22; and what I, actually, find superfascinating, is, for our age 3 kiddos we had a ton of kids that got identified in 2020, and then we saw a huge decrease in '21, and those numbers still haven't really recovered too much in '22.

So I -- I think that's really interesting.

To consider, you know, --

thinking about when our kids actually being identified, when are we seeing them...

Come onto the Child Count, and all of those sorts of questions.

>> Carlie Rhoads, PhD: And then my final graphic, for you-all, because I'm sure not everybody is as excited about numbers and data as I am, I didn't want to bore you-all too too much but these are our top three etiologies for the last three -- four years, and this is a comparison, of birth-3 versus 6-21, oh, no it's specifically for just the year 2022.

But these were the top four etiologies, for 2022; and it was complications of prematurity, CHARGE syndrome, if there is no determination of etiology, and then we have kind of a catchall category of "other" that tons of kids fall into typically.

And if you look at the orange line that is the 6-21 kiddos; and the blue line is 0-3.

And, you can kind of see there is quite a huge gap because, our 0-3 -- like, -- the highest number it looks like on there is hovering at the 200 mark, whereas the highest number for 6-21, is, you know, well over 1800.

>> DR. RHOADS: So really, really really big difference and this is really telling about how quickly kids are getting identified, when they're coming on the -- to the Child Count Database.

Lots of implications for receiving services.

All sorts of things.

(A pause), (as slide advances), so I just wanted to touch on some potential issues, just surrounding identification that we typically tend to see, serving students with DeafBlindness: First and foremost, there seems to be a real common misunderstanding, just around the term "DeafBlind", you know -- we see a lot of people, You know, -- families, professionals that have not been exposed to DeafBlindness before and they think oh, you know, this student is not DeafBlind because they're not completely Deaf and completely blind.

And I will tell you, Like, if you look at our database, you will actually find that only 1% of all the kids on the database, are completely Deaf and completely blind.

DeafBlindness is a spectrum, In terms of vision and hearing and there's all sorts of combinations that come with that.

So, a lot of people don't understand that just because, you're not totally Deaf, and totally blind, that you can still qualify as being DeafBlind.

>> DR. RHOADS: We also typically see a lot of delays, in this whole process, of diagnosis, referral, and actual implementation of services.

There is a great academic article, that I believe is by Boyer Hatem and ivy, done in 2010, it's a little bit old but most recent one we had, what the delays were between diagnosis, referral and services, And, even if a child, was diagnosed, like, -- within, three months of birth, delay oftentimes were not receiving services, until they were well almost two years old.

That is a huge, huge, huge problem.

So, again, that's causing issues around identification.

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>> DR. RHOADS: There is also sometimes perceived stigma.

I -- I served as the Director of the Oregon DeafBlind Project for a couple of years and I definitely had a lot of conversations with families that were just, like, -- absolutely not, you know, my child is not DeafBlind.

That's -- that's not my kid.

And, again, that's whole misunderstanding about what DeafBlind means, and, people not understanding, and being nervous about that.

So, sometimes that impedes kids getting identified and being put on the Child Count database in a timely manner.

And then, of course, an issue around identification -- that pesky pesky pandemic that I'm sure everybody's sick of hearing about.

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>> DR. RHOADS: Our numbers are really, truly, beginning to, you know, finally stabilize, in the year 2022.

I'm excited to see our numbers and data for 2023.

Typically state DeafBlind Projects our data submission window opens March 1st and closes May 1st typically so it's going to be soon time for states to start submitting their data for 2023.

And, I'll be really curious to see if our numbers, are continuing to stabilize.

Or if, you know, we see, like, a really wild increase or decrease, you never know what's going to happen, but definitely the pandemic had a huge, huge impact on identifying kids, and getting the proper numbers, And that's why, with a lot of those graphs that you saw, you saw a really big jump in almost every single category from 2020 to '21, because, of the pandemic issue.

(Slide advances).

>> DR. RHOADS: So if we -- just to give you guys some questions to consider when we open the Q&A.

I do know I have talked a bit, so we might not have time for all of this, but if you want to talk about some trends that you're maybe seeing with early-identification -- in your area -- what you think might be some other issues, impeding identification, And -- if you have any sources or supports -- that you know of -- that could be helpful for increasing early-identification, feel free to soundoff about any of this or additional questions In the Q&A.

(Pause).

>> DR. RHOADS: And I did want to throw up my e-mail address and Emma's.

I have standing -- office hours, that anyone is welcome to attend on Thursdays, for an hour, at 3:00 eastern time.

So, if you ever have a question about the database, if you have a request for specific numbers to be pulled.

Anything like that.

I'm always happy to talk about that.

And, of course, if you can't come to those specific office hours, I can meet and talk to you in other times as well.

I just like to have a standing office hours, and I get random people that pop by all the time.

So -- so at this point, I'll kick it over to the question-and-answer section.

I think I see a couple of comments, maybe in there.

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>> DR. EISERMAN: Yeah, so we invite you to use the -- the Q&A box, and to which you can type your comment or question, and the first one, is with many states passing laws dealing with.

Congenital CMV, can people still refer the kids to their state DeafBlind Project?

Or DC -- NCDB if a child has asymptomatic CMV?

Because hearing loss and/or vision loss can manifest later or do they have to wait until the system -- the symptoms are present?

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>> DR. RHOADS: (Answer), that's a great question so just to clarify, NCDB, we don't do referrals, it's the state DeafBlind Project specifically that do.

And honestly that is a call that varies from state DeafBlind project to project.

I know, like, for instance when I ran the Oregon Project, we would -- welcome, and put kids on the database, that, may not have a profound hearing and vision loss at the time.

But if it was, you know, -- it was coming, and we knew it would be deteriorating, we wanted to go ahead and get them on the database, and start them getting services and those sorts of things.

It just really depends on the state.

Every state has slightly different... eligibility requirements.

For DeafBlindness.

You know, some states -- if you are eventually going to qualify for a Deafness and blindness, they will go ahead and put you on there but some states you have to meet a minimum requirement for high acuity and those sorts of things and it depends on what your state is.

>> Emma.

One piece of what Carlie saying and I see Heather -- we have a number of state DeafBlind projects folks on this call, so Hi, everybody, thank you for coming!

But Heather wrote, we are seeing an increase of much earlier diagnoses of Usher Syndrome, specifically in babies three to nine months old versus when they start losing their vision in their teens, this has been very impactful for families to get support and be proactive instead of reactive.

And that's -- that's so true.

And I think Heather, you're in Iowa so it's great to hear that's what's happening in Iowa, I know for example in Arizona, if kids are identified through genetic screening for having Usher Syndrome, they are not able to be placed on the Child Count based on their --

Based on the eligibility requirements.

>> Emma Fricke, M.S. Ed.:

(Continuing), but there is a lot of information that's being disseminated about that and so it's kind of this waiting in the wings.

Here's -- here's what you can do in the meantime.

There are some great resources that we worked on with the Usher Syndrome foundation, around early identification and early supports which I can be sure to share as well.

>> DR. EISERMAN: So a question from Illinois: Why delay to provide services, for DeafBlind babies, until age 2?

This person says, "I am from Illinois, and I work with the Hands and Voices guide by your side parent guide.

I had a child with DeafBlindness."

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>> DR. RHOADS: So I don't think it's necessarily a rule that services get delayed until age 2.

I was referring specifically to a -- like, a data study that was done in 2010 that saw, like, on average, that there was a delay, between diagnosis and referral, and then referral and implementation of services.

and... you know, just based on my experience, it's just bureaucratic red tape, like, that tends to happen.

Like, it could be that, there's a diagnosis, at birth, and a misunderstanding that DeafBlindness applies in that case, so then, the referral and services part, like, doesn't happen until much later.

There's lots of reasons that that could be happening.

But, you know, historically, I think those delays do tend to happen, and, I think, education is really key for combatting that. You know, making sure that, like, -- medical professionals know that, you know, "Hey,!

If we have a baby that's been diagnosed, you know, with CHARGE syndrome that we might want to hook them up with their state DeafBlind project", you know, things like that.

>> Dr. Eiserman.

I want to -- go ahead Emma.

>> Emma Fricke, M.S. Ed.:

Sorry, yes, and one additional piece, that I think is so important, and why you-all might be getting tired of hearing from us so much is the importance of partnerships because -- we -- there's a very large difference between identifying kids as DeafBlind, and having them on the Child Count; and then, actually, having families receive technical assistance from state DeafBlind Projects, so state DeafBlind Projects maintain their state DeafBlind Child Counts, deidentify the information, and report them for the National Child Count, and that information is critical for us.

And for the -- for the office of special education programs so that we can have a strong understanding, of these trends that Carlie has shared about who is DeafBlind within the United States and about -- um... what kind of services and supports they're receiving, and that really, then, helps us to.

Define how -- how we all do our jobs, at state DeafBlind projects and at next CDB, so having a strong

understanding of what this data looks like is one piece.

And then, there's this piece of technical assistance, to service providers, technical assistance to families, with which dan DANA talked about in the webinar in November if families aren't ready to receive technical assistance from state projects, there's still an opportunity for them to be on this national Child Count and I think that --

That has not been solved yet.

It's how do we talk to families about this Child Count, without necessarily, overwhelming families, or making -- making, the -- the assumption that, oh, there are so many people, already on the team, we don't want to add one more person, there's so much there, and I think the only way that we can figure this out is by having those open discussions with each other; and really brainstorming how that -- how that can happen.

And that would be state by state.

But, yeah, that's -- that's a soapbox you guys hear me talk about all the time, but it's an important one.

>> DR. EISERMAN: You talk about state by state engagement.

How can state EHDI programs staff support... the DeafBlind population?

And these -- these counts?

Both in terms of accessing services as well as in getting --

An appropriate count?

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>> Emma Fricke, M.S. Ed.: That is -- that's the golden question and I love that you asked that.

Partially, that's this work that we're all doing together as some of you, I know, were attending a work group, after the EHDI Conference where we can have this conversation.

And -- and really start digging into what that looks like.

I think the -- there are a number of different states who are doing a number of different things, for example, I know some states are working on MOUs between their EHDI programs and their DeafBlind programs around some data-sharing, there's additionally, some questions with....

Really -- actually, -- next month, in February, The Minnesota DeafBlind Project is going to share how they're really working on integrating questions around vision so that it can become... more -- I don't know if you want to write in the chat anything specific, but they're really working on integrating questions about vision.

So that potentially, vision can be identified earlier.

Another piece, is just, really talking about what that referral process can look like.

How that can be completed and by whom.

Anyone can refer.

And so, uh -- let's see, I --

is there anything else Carlie that you want to add to that list?

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>> DR. EISERMAN: Well, I want you to say, again, what's happening at the end of the conference.

>> Emma Fricke, M.S. Ed.: Oh, sure, so we -- are so -- so, excited to have the opportunity, to partner

with all of you, after this conference, to have a work group.

It's going to be a small group of -- at the actual conference but then this work can continue on.

With a larger group, and so for interested people who really want to dive into this question it will be, how can state DeafBlind Projects -- and there will be state DeafBlind projects folks there, as well as EHDI and Hands and Voices, partner better to support families, by identifying kids as early as possible?

And I think we all recognize that, so many different hands are in so many different pots, and then there's, you know, etiology-specific supports.

There's so many different supports, And, so, by putting all of the questions on the table, and working together -- I think that -- hopefully, we'll get somewhere.

And so this work group will be -- on that Wednesday, after the EHDI coordinator's meeting and the family-based organization meeting, it will be that afternoon on Wednesday, and, -- we'll meet from 1:30 to 4:00, we'll have coffee, tea, some snacks, And --.

>> DR. EISERMAN: And if they want -- if somebody wants to participate, how do they let you know?

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>> Sophie Page, sent out a -- an e-mail, I think it would have been through -- through the National Center for Hearing Assessment and Management, I believe she sent that a few weeks ago and then she sent it out again, either yesterday or today.

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>> Emma Fricke, M.S. Ed.: You can also just e-mail me directly if you're interested.

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>> DR. EISERMAN: And Emma's e-mail is on the screen right now!

We realize, that some people are needing to go.

But, we can stay on, for a bit longer, and answer a few more questions.

So, I -- I cut you off, Carlie, did you have something to add to what Emma was saying?

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>> DR. RHOADS: No I just wanted to, you know, really -- you know, -- reiterate, like, how important this work is; just because, you know, -- the faster we can identify these kids, you know, the faster they can get referred and the faster they can get services and we all know how critical early intervention is and just, like, how important it is that these kids, are getting intervention, as soon as possible.

And, , you know, I think at the core, that is really, like, why this is so, so important.

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DR. EISERMAN: So --.

>> Yeah.

>> DR. EISERMAN: The next question, I'm a nurse with --

with three -- three children, two with Usher Syndrome, type 2.

I went back to school, and became a teacher of the Deaf, and -- and also, help out with the Idaho EHDI Project I refer kids to Idaho DeafBlind Project for my 0-3 students, I think there needs to be more education for teachers of the blind and teachers of the Deaf, to bring this up with parents.

Also, I think referral to genetics in terms of Usher Syndrome -- will help as often those don't get diagnosed, until much later.

I had genetics done very early, and I'm so glad I knew earlier.

(Pause), So that was a comment.

Essentially.

Any responses to that?

(Pause).

>> DR. RHOADS: No, I think that's a really great point, and, again, you know, just knowledge is power.

And, you know, -- I -- I do think, you know, that -- in personal prep programs, like, you know, TBis and TODs do need to be taught more about DeafBlindness and what a state DeafBlind project is and those sorts of things and there's definitely lots of room for growth and improvement.

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>> DR. EISERMAN: Next question -- do you have statistics, on the numbers of DeafBlind children who use ASL?

DR. RHOADS: So -- (sighing), yes, and no -- and I -- I hate to have to say that.

So, we do have a category that asks, like, what the primary language spoken at home is.

And -- but the thing is, that's an optional category, so not every state collects data on that.

So -- and, again, -- only if the primary language in the home, is ASL, like, would they be reporting that.

So -- unfortunately, we don't have, like, a lot of hard data about how often ASL is being used with the kids.

(Concludes answer).

>> Emma Fricke, M.S. Ed.: The other piece with that is that it's possible that your state DeafBlind project does.

They oftentimes may collect certain states may collect more information than what is reported on the national Child Count so they may have that information; and you could reach out to them.

There is a state DeafBlind project directory on the National Center for DeafBlindness.

Web -- Web site, if you scroll down, it says "contact your state DeafBlind project" at the bottom and then you can scroll through the directory and they might be able to give you that information, or at least a ballpark.

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>> DR. EISERMAN: Two wrapping-up comments and then we'll tie it up for today, but before you-all go....

Look in the.

Chat field.

Where you will see, a link to an evaluation for today's webinar that will also generate a certificate of completion for today's webinar.

If that's important for you to document.

So, please look there before you run off.

So, a couple of final comments:

Or questions -- somebody --

typed in that babies count, babiescount.org tracks babies who are blind, it might be another good partner to reach out to.

As some may have DeafBlindness.

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>> Emma Fricke, M.S. Ed.: Yes can I say one thing superquick about that?

Yes, absolutely, we have been having some preliminary conversations with them, one of the interesting things that often the same person that would submit the babies count information, may be the same person, who would confirm the --

The state DeafBlind project Child Count information, per year, or may submit that -- that referral.

And so often that person could be the same person, and so, it's always an interesting thing to -- to have conversations about.

For sure.

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>> DR. EISERMAN: Yeah, there's people who wear multiple hats.

(After a pause), just a question about the post conference meeting: Is there any chance of virtual participation?

Emma Fricke, M.S. Ed.: For that -- first meeting -- there will not be; however, going forward, this is -- that -- that is a very brief kickoff, to really think about, and put --

just all of the things we can think about on the table; and then from there, there will definitely be continued opportunities for this partnership, and -- um, for conversations, whether that be, through Zoom and breakout rooms or other things like that and so definitely, stay tuned for that information, Theresa.

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>> DR. EISERMAN: One final QUESTION: So this person -- maybe, there's two final questions.

W This person writes I'm a teacher of the Deaf and would like to know if you have any ideas about how to get our district to use DeafBlind, on the IEP.

Instead of multiply disabled.

Any thoughts?

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>> DR. RHOADS: Oh, that is a good question!

Because that is a battle I have fought, many, many times (chuckling), when I was -- in Oregon, the Department of Ed would only count the first two eligibility categories.

So if DeafBlindness was not one or two, that kid was not being counted as DeafBlind.

And -- honestly: You know, the case I typically make -- you know, to a school district, like, in that kind of a situation, Is just, like, -- explaining the difference between what multiple disability means, versus, DeafBlindness, because, DeafBlindness is truly getting at the heart of a dual sensory loss.

Like, -- those interventions, those services, those needs, those accommodations -- are superspecific. And if it is not specifically listed that DeafBlindness is what that child has, and what they need -- then they're not going to get the appropriate services that they really, actually, need.

And this also has ramifications, in some school districts, because, you know, if you have 100 kids with DeafBlindness but only 10 are being reported, well, guess how much money is going to be allocated for funding for those kids?

Like, not as much as they actually need.

So, making a case, like that, can be really helpful.

And -- again, if you need numbers, from the Child Count specific to your state, that you feel would bolster your case, please e-mail me, I will put those together for you. I would love to help you.

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>> Emma Fricke, M.S. Ed.: And we also just had an article published through the Journal of Special Education, where, some things that impact identification, were listed, and one of the things that's really interesting, is that the OCIP numbers couldn't really be used because they're so small so they used the National Child Count, and I think the more that --

we -- you know, we've presented it, OCIP about this challenge, I think the more that -- that we are aware, the more, that, then, people can really advocate for that DeafBlindness, on their -- on their IEPs.

DR. EISERMAN: And a final comment from one of our Participants, and remember, everybody, to check the chat field before you -- you run off to get that link.

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This person is -- is Tony Hollingsworth, who is in -- the Mississippi Hearing Vision Project to comment. Children born with vision loss are not associated with any child registry, as there is nothing equivalent to the hearing screening at birth.

Therefore, those who are identifying hearing loss, in each state are not necessarily aware of how to refer to services.

Each DeafBlind project in each state, has to reach out individually, to all of the pediatric ophthalmologists, et cetera, to inform them of the services, of the DeafBlind projects.

Any comments about that comment?

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>> Emma Fricke, M.S. Ed.: Yes, and mostly thank you, Tony, for -- for writing that all out and for sharing.

Yes, -- and -- and I think, that is where, there is so much complexity, just through this conversation and there is no easy answer and why I think, some of the common etiologies associated with DeafBlindness, as red flags can be really helpful because, then, they're in the back of your mind, as EHDI Coordinators, to be, you know, speaking with your audiologists, okay well, if this child has CHARGE or if this child does have a lot of complications due to prematurity just to keep that in the back of your mind and with guide by your side programs as well and it is a huge, huge task, and state

DeafBlind projects work so, so hard to find these babies.

-- and to build these connections and it is such a web, and I think the more that -- that we have those honest conversations, and really try to dig in and figure it out, the -- the -- the more progress we'll make together.

(Pause), .

>> DR. EISERMAN: I really want to thank you -- both of you -- and to our captioners, and our -- our interpreters, today.

I want to just, also, mention that, for those of us who have worked at -- a lot myself, specifically -- in later onset hearing loss identification --

A lot of those initiatives are -- are combined under the heading of "sensory screening efforts." Vision, and hearing being combined as a part of those initiatives.

Prevent blindness, which is one of our -- our Partners, has some resources that are useful particularly for the three-five-year-old population, but some guidance for younger levels for vision screening, and that's another set of resources that would be helpful to -- for any programs to be aware of.

When they're interacting with folks who are really coming, to the table, with that larger question of sensory screening.

So -- just another resource to think about.

Thank you, everybody, look in the chat field for a link there, that link will take you to a quick evaluation of today's webinar.

And will also generate a Certificate of Participation for today's webinar, if that's helpful to you.

Remember this webinar has been recorded.

It will appear on our Web site in the next couple of days, which is infanthearing.org.

And keep in mind, those, who may not have been in attendance live today --

Who may benefit from learning some of what we've discussed today... also, watch for that e-mail.

From Sophie Page at Utah State University Who -- has information for you, about the post EHDI Conference Meeting, that Emma was discussing.

So -- or you can e-mail directly, to Emma, if you're interested in participating in that.

Thank you, everybody, .

>> Emma Fricke, M.S. Ed.: Thank you, all, so much for being here.

>> DR. RHOADS: Yeah, thank you so much!