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EHDI Annual Conference 2024 - Topical Session 3 & 4

3/18/24

3:25 PM - 5:40 PM (MT)

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(Captions provided by a live Captioner.)

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START TIME: 3:25 PM

(Captioner Standing By)

>> Hello, this starts at 1:55 p.m. With that, does anyone need access? Interpreters are...perfect. Thank you for that. So, welcome. We are going to talk about the hands of voices family support activities guide. We have plenty to share and only 25 minutes, so we're going to get rolling. All right, so I'm Carrie Balian. I'm a guide by your side programmer. Lisa will introduce herself when she comes up.

We're going to talk about EHDI's full circle on support and how this plays into that. The EHDI program oversees the 136 of screening, follow up and getting into early intervention. Relevant and timely support and intervention are important for families of children identified with the hearing loss because majority of these children are born to hearing parents and weren't expecting the diagnosis. So JCIH has identified parent to parent support as

component for children with hearing loss.

It supports guidelines to family to family support for goals 8 and 9 in 2019 supplement. So on this link we have a slide referencing the EHDI act of 2022 which states that programs and systems shall offer mechanisms that foster that family to family supports. I can forward, so some EHDI programs have been adding to the goal of 1, 3, 6 with the plus to have that addition of family to family support and deaf and hard-of-hearing role models.

>> I'm seeing folks I know. Okay. Technology. All right. So hello, everybody. I'm Lisa Kovacs the director for hands and voices headquarters and on the family leadership and language and learning center core management team. So first of all, before we jump into the newly revised family support activities guide, I wanted to talk about hands and voices implementation of family to family support. How many of you are familiar with family to family support. That's the first time I seen the majority of the room. For a few of you who this may be new, this came out of western university and researchers Henson and Johnson, from 2000 to 2014 they were reviewing peer-reviewed research articles around implementation of parent to parent support as researchers they sought the opinion of 31 experts from seven different countries around the delivery of parent to parent support and myself and the director of hands and voices headquarters had to be involved in the ground work of establishment of framework with 29 other folks. So after completing online questionnaires and considering languages in other countries as well, we came up with this framework that looks at the three main constructs for families, the well-being, the knowledge and empowerment of the families. So, when you see the arrows going around the outside of hour glass, this is the learning parent on one side and the supporting parent or that could be the supporting deaf and hard-of-hearing leader to family as the support on the other side. And it goes to show there's this existence between a relationship in all of these constructs, meaning that not only is the

supporting parent or the deaf and hard-of-hearing consumer contributing to the learning parents knowledge, well-being and empowerment but there is contribution and connectedness back to that person providing the support. We grow in our skills by every family we work with.

So have you all heard about the maternal-child health bureau's blueprint for change? Most of you. So here you see on the left side of this slide, and this framework is to highlight the vision of services for children and youth for special healthcare needs. Families reported through a national survey at children's health in 2022 how the current system of care not working for families. So through that information they have established what is called the blueprint for change that outlines four critical areas, health equity, quality of life, well-being, access to services and financing services.

When I first saw this and heard about this movement for all of us to be considering these four critical areas immediately my mind went to our conceptual frame work for family to family support because within our framework and you can see on the slide in my arrows when you see access to services that's in our knowledge construct already. It point over to specialist in services, so we already have established family support activities that providers can use for families to help access services.

Secondly, when you look at financing services, that also it may be too small to see, but under construct we have services in conceptual framework and quality of life and well-being is one construct of construction framework and health equity is infused in all three of those but also is spoken about a lot in the empowerment construct.

So hot off the presses and once you're here to hear about is our new hands in voices activities guide. In 2019 through Hanson voices and work with guide by your side and 20 parent leaders for 14 of guide by your side programs, we established the first parent to parent somewhere activities guide. If you're in the room and part of that first version addition, thank

you, will you raise your hand?

Yes. Awesome. So we really appreciate the work they did and through time our guide by your side programs utilizing that resource we decided why keeping this locked under keep, but why not share it out there for deaf and hard-of-hearing leaders providing support to families as well as changing some of the language in it so that if families fumble upon this themselves, they can find it themselves as well. So hands in voices created the guide providing learn outcomes so in each construct we have five family learning outcomes. What we hope the family will learn in well-being, knowledge and empowerment in the time they've been provided family support and we also have supporting activities that are very family friendly to build the skills and understanding of the learning parent. This guide provides activities and learning in a simplified format and it highlights topics provided through a goal, so a family learning goal in each section allowing users to find activities that are related to their needs.

Our role in supporting families, we can use this guide to target the needs of families we support and quickly provide them with resources through the included activities. However since this guide is available on hands in voices Web site all of you will have access to it and we took into account when we set the tone to the guide. So here you see these arrows on outside of conceptual framework and you see that knowledge, well-being and empowerment has impact on the family's knowledge and knowledge and empowerment impact the well-being, so all three constructs really influence each other, so we don't want to just be staying in the well-being construct without thinking about what are activities we need to do with families in the knowledge or empowerment area and we don't want to be empowering families and not think on what knowledge they need.

So a little bit about each one of constructs and I'll turn over to Carrie. So this is the first

construct and it includes topic areas like self-perception, inclusion, monitoring goals, bonded bonding with your child and coping. In the second construct knowledge here you will find activities that focus on themes such as advocacy, system's navigation after transitions and education. It starts with understanding the laws and the plans created by the team and ends with understanding who provides these services for families and the importance of engaging and language and knowing how to trouble shoot technology. And the final construct empowerment this focuses on helping families feel administer confident and competent in their role as a parent.

This construct represents topic areas such as importance of family engagement, making decisions, safety for their child and acceptance and finding solutions for their family. Turn it over to Carrie.

>>CARRIE BALIAN: We made sure the link still worked and that they were relevant. We reworded things and we added new resources over those 4 or 5 errors since it was created. We developed so many more resources at headquarters, so we wanted a one stop shop and we take the time to hyperlink and highlight additional languages, so 68 Spanish resources and over 25 other languages available in different activities throughout this guide. And we have also like Lisa mentioned started each construct with the family learning outcomes, so what five things can a family expect to gain from that area.

So you have a sneak peek at one of the pages. You see with the turquoise coloring at the top of that graph it shows that you're in the first construct of well-being. In addition you see the highlighting and hyperlinks and this draws attention to language and literacy.

So at the start of each one of the constructs is we've created visual indices they coordinate with the coloring of the construct but these are hyperlinked in using the PDF version or web version where you click on that and it will take you directly to that section of the

guide making support a breeze and hopefully with topic areas broken down it will allow families to easily see where they need to go or what options they have to share with the family.

So the smiling icon as I mentioned earlier that highlights language and learning activities and I mentioned that all the activities or resources are in one place now. There are 192 resource links and 160 are unduplicated, so a lot of fresh information. Not like here we go again going back to that resource. Not that. If you're using the PDF version you can use the search version control F to find a particular language you're looking for or particular topic or idea.

You can use that instead of using that visual index. How did you familiarize yourself with this. So several different ways use visual indices I know that they're going to print out each visual index and keep handy so they know where to go quickly. Tuck split this up and do a training and have the team choose a particular construct and shear activity from that and another part of team use a different construct. You do role-playing.

No one likes it but it does help. It puts you in uncomfortable spot to keep you on your toes. I created a bingo game for the well-being construct. It will be available to programs where they use the bingo game and print out if in-person or a virtual things as well but pick a topical area and mark off bingo area, and go to that area of guide and read the activities. A fun and easy way to get familiar.

So the family and learning outcomes as we discussed at the bottom of these pages the start of each construct area you see the bottom there it says family learning outcomes and those are the five things that a family should be gaining from that section such as construct one, the third learning outcome is be able to improve focus on every day moments that bring the family joy.

So maybe you want to ask the family a question, what are simple happy moments you

discovered as a family while navigating the child's journey. How do you make space for those in your day? So consider using in guide at the start of each construct as a tool to determine where the family is and when they might be ready to move on either from that particular concern or maybe from the program, itself, right? My team said how do you know my team is ready?

We've heard some programs would consider using this before they start working with the family and revisit after they work with the family and discuss some things. So you've received a cute happened out highlighting web page on happen to voices web site off to a great started. This here has a large variety of things, so if you click on the rocket ship it blasts you off to a particular resource. When you hover over different areas with your mouse it shows you what that resource is for. So with that, we wanted to highlight that little chalk board says family support activities guide that is the complete guide. There's three balloons in three specific colors and you can click on that specific color, the turquoise for well-being and go to the well-being construct.

So we hope that you use this. We weren't able to add the QR code to the slide. But you can find after the presentation. I like quality improvement, so before diving any deeper I took it to my team. I said here's a copy of this guide and they saw eight out of the ten. They seen the first version of the guide and she saw the revised one. So in addition to that I created a tip sheet that will be used a training tool to go along with this and we plan on creating a video. I did create the video from my team and it wasn't captioned or anything like that, so nothing final or headquarters to use, not yet, but we will get there, so with that, on the slide, we had asked after reviewing the video and tip shows how do you feel to use the guide.

How I like the guide working with families. Four out of five ready to use that. Quotes are everything. So this is a quote from one of moms on my team, she said, I admit a little

overwhelming at first but you acknowledge that in the video after taking time to watch the video, review the tip sheet it makes more sense and utilizing will be so much easier.

Awesome resource, tip sheet located in one easy to access place now.

>>LISA KOVACS: So I wanted to share that prior to the revisions of the guide we different several focus groups. We received their feedback and we simplified language, some said I like in a long PDF version. Some said I would never open that PDF version, I want it electronically. So now it's available off to a great start came about, so not only seek user feedback in the changes but sought their feedback after done to make sure before I called it final.

>>CARRIE BALIAN: So we're going to leave you with a final few thoughts about using the guide with families. Go with the flow of the family, sit this silence, let them produces. One of my favorite acronyms is tiny. Sit in that silence. Let them create their own story. Don't be overwhelmed. So like any TAF if you're overwhelmed by the guide, start somewhere. You don't have to tackle the right then and there. You don't have to do it in one sitting. When working with the family don't hesitate to tell them you're unsure or don't know. You can review the guide afterward or text them that link later on. So a couple of tips there and we're done. I don't know if any questions.

>>LISA KOVACS: Just two other things, I don't think I heard you say, we're getting ready to post a tip sheet on how to use the guide and going to create a training video that guide by your side programs other FBOs can use to train family support staff.

>>CARRIE BALIAN: Excellent. Heidi?

>> When is the video going to come out?

>>LISA KOVACS: Sometime in April.

>> Just a technical question, where is the PDF version available?

>> It's on orange tag when you saw the --

>>CARRIE BALIAN: Not PDF on the Web site. On the Web site instead of putting the PDF, they actually put the text on the Web site. We're talked back and forth, which is the better move. One thing I libel about the text if you have family using additional language they can use Google translate. I know not perfect but all of that would translate to their language. The PDF is searchable. So we have two sides of the sword.

>>LISA KOVACS: We'll make it available PDF. We just wrote out with web master, but you can e-mail me and I'll seen you PDF version of it. We'll get it posted for those how who want to print out a 35 page copy. Any other questions? I think we're done. Thanks guys. See off to a great start.

>>ANDREA MARWAH: Welcome, everybody, I'm going to go ahead and get started, so we have enough team. I don't know if we'll have time for questions. If you don't, you can find me somewhere and I'm be happy to answer for you.

We'll talk about socialization skills for kids deaf and hard-of-hearing. We'll walk that path and what we can do toe support them with that. I work to have Illinois school for the deaf. My watch is going crazy right now because I have a family IEP meeting now. I also and the Executive Director or Illinois hands in voices chapter and I have several topics I love to talk about. Enjoy in 25-minute ride.

What about socialization why so important? Why are you all here? It makes us happy. If we don't have friends, we're not happy, if we don't have our circle of people, we're not happy. It has been shown in research that if an individual has one true friend, they can be happy. So it's not we don't need -- I always think of Facebook pictures where 40 people in the prom picture. We don't need that to be happy. So don't think they need those big groups. Those groups are difficult for our kids. Having friendships, learning how to maintain lasting long

friendships.

Having a support system for when things are not great or when things are great and you want to share great times. Think of economic factor. We have to be able to cooperate with others in the workplace and understand the social norms and social things required of us and what is acceptable and what is not. Work ethic, longevity in employment, all of these things stem from our ability to be social humans.

The learning factor. What do we do in school we're we learn together. As early as second grade putting kids into groups to do projects and work together, that's how we exist as humans. Not many things that one sole person does. It's typically many. We need to learn how to do this and how to cooperate in a group and work in a group so we can get things done.

We have tons relationships and how he work and how we keep them successful. So what are social skills? It's knowing what is appropriate and when it's appropriate. It's fulfilling the expectations of others. Ever hear of theory of mind. I redeveloped my presentation on theory of mind, so I'm geeking out on it right now. Ability of me to understand by looking at all of you don't have the same thoughts I do and that's okay. I'm not ego centric, I understand it's not my point of view and my theories and my thoughts. Being able to interact with others.

Inhibiting inappropriate responses and respecting others. And building relationships. So why are social skills difficult for students who have deaf and hard-of-hearing. They're not always difficult. Some of our kids go through life and never have those complex interactions. But some of ours find it very challenging and some of you who's our parents in the room? Some of us as parents, me being one on them, have a cry now and then because our child says they have no friends. Where is the missing link and how can we fix it now. We have these things that happen.

So it can be difficult because he have delayed language development. Their language may not be at the same age as their peers which makes it difficult. We have delayed levels in observation edging over to the kids, because they can associate with them better.

It's hard to make friends if can't communicate with them. Limited experience with books and reading. Parents read to your children. If you think they cannot understand them read to them and discuss what you are reading with them. The best thing a family can do is have a family book club. It helps to understand. If you read a book it's a story about someone's experience, social experience, right? So these are the perfect opportunities to talk to your kids about that. Limited incidental learning, right?

That picking up stuff just from being. We miss that. And lack of perspective talking or seeing things from another person's perspective or point of view, theory of mind, right? Well the US Department of Education gets this and they've written a position statement is that says the communication nature of hearing loss can be isolating. Inherently so. So we know this, right? So that means we should be doing something about it. We should in fact be viewing all of our kids in the lens they should potentially have social skills concerns. We need to do that. I remember the first time that I contacted my school and said I think my daughter is having social interaction issues. I think she's having trouble with friends. The social worker said I'll observe her and she went to the play ground and called me. She said you have nothing to worry about Samantha is convene of monkey bars. Was she interacting? But a lot of kids watching her.

Without that deaf lens she doesn't get it. We know it can be inherently isolating. So core curricula says if we explicitly teach social skills are kids can be successful. We need to expect it with our kids so we have it in our mind's eye. We're always watching so we don't have to backtrack with 18 and 19-year-old. So think about that. So why is socialization a

language challenge? Well the implied can imply through the tone of voice or the word choice they use or make hints that our kids might miss.

The listener or the receiver needs to infer what is meant by the conversation that's taking place. You need to be able to fill in the blanks. What might the listener receive or understand from a communication or what is missing from the message that might make it clearer and what does the message reveal about the speaker. So how we use language socially we tell things, hint things, promise, ask, we have different word choices depending on what we're trying to express. Intention is there as well. What about formality, do you talk the same to your grandmother as your best friend or your boss the same as your friends at school.

We have kids that don't get formality and talking to their teachers in ways that they should not be talking to their teachers. We need to teach that. They don't know unless we tell them. If their body language is aggressive, shouldn't be aggressive in that instance.

Perspective, the ability to take into account what others know. I'm making a big assumption talking to all of you, you know, a little bit about hearing loss, just a guess, but I'm making that assumption based on where I am and based on the fact that I've talked to many of you in this room in the past, so I know you know a bit about it. So I do trainings like this for professional development and I'm walking into a roomful of individuals who are teachers by trade but nothing about the needs of deaf and hard-of-hearing students, so the way I approach the learning for that group is different than I approach it with you.

Structure, understanding that turn taking clarifying, keeping to the topic, right? Understanding that there's rules to social interactions. So what can you do to support language and social skills and this is everybody, moms, dads, grandparents, we need to get them to understand feeling words. Feeling, feeling, feeling. And understanding that there can be feeling words that are different that mean the same.

Because if our children do not know that angry and mad mean the same thing and someone says I'm angry with you and they laugh at that, that's going to get a negative response. But what is that? It's a learned thing. They do not know that word because it was probably automatically acquired by the rest of the kids and they missed it. Teach emotion words all the time. Look at emotion words in this square. These are just a few, but many on here are not words we use every day but I can tell you will see them this written text, if our kid DOS not know what they mean, they're going to miss the meaning of that text.

Use emotion in communication, facial expression, body language, make sure they understand from what you are doing with your body and your voice and your hands, he's signing and he's got expression, making the receiver understand I'm serious about this. If just standing there with no expression harder to understand what he's saying.

Express how you feel. Who are my providers in here. If you walk in and ready to work for kiddos. Tell how your day has been. Maybe you woke up late and frustrating morning help them to understand you feel those things. Talk about social pictures. Talk about books, TVs, movies, videos, role-play situations in the moment. Not always easy. If I have a roomful of education interpreters I say stop in the middle of the hallway and say let's look around what do you think going on? I guarantee there's a boyfriend and girlfriend fighting over there and something going on over there that our kids would normally miss but what a perfect opportunity for them to want something is going on next to them.

And what do you think they're feeling right now? Ability to observe. So this is just idea of what a social picture could be looking like, right? Normally if more than 25 full minutes I would ask you to tell me what's going on in this picture but I'll do it based on what people have told me and I've this for five years, the same picture and some people say the girls in the foreground are talking about the girl in background and she feels sad and left out and people

say the people in the foreground is talking to the boy in the foreground and she likes him. Maybe he doesn't like me. It doesn't matter what's happening, can we pull out numerous things that could be happening based on the facial expression, the body language of what's going on in the picture and I turn it around and say what if the people in the foreground are making plans for a surprise party for her and she doesn't know. More often than not, that's assumption.

They're making an assumption that they must be talking about me 'cause I'm not included. Children with hearing loss don't always overhear what is said. They miss that incidental language. Another reason they may miss the tone of the message, so they might say what it is but they might not understand that I'm elated, happy or frustrated and angry or that I'm sad. Inappropriate response, if I'm sad about something but I don't show it in my body, I shared my pet died and they're not getting it, they don't understand. They miss the intent of what that communication is meant to be.

This is just a perfect example of identifying the hidden social message just based on your voice and how your intonation or the interpreter and the way they sign it. So okay, we're going to go through this. Okay, do you agree? Oh, okay. Now I'm concerned. Or oh, I agree, I get it. Or resign to the fact, all right. Okay. So we can go and then what happens parents in the room raise your hand. Your kids have beaten you up. They want to do something and you say no, no, no, you had enough, what would you do, get out of my face, go do it. So depends how I say it is going to depict the message I'm trying to get across. What can you do to help develop social skills. Think out loud about your problems. Go through the mental processes that you go through when you have a problem. Weigh the possibilities, what types of questions you ask in a situation and share your decision and reasons for decision. Give opportunities to think through a problem themselves or with peers.

They need perspective taking discussion that's in the moment. They need to understand truth versus mistaken belief and they need to know how you know that. But they need to understand what different types of communications they can have in social interactions. Remember to always have what? We have very high expectations with their behavior, with their responsibility, and with their social skills. My daughter is 22 years old and a senior at Rochester Institute of Technology. He graduates in May. Super excited. Not easy for her, deaf and introvert. We have to know those things about our children too and we have to understand what they're bringing to the table. We need to make sure we affiliate in the blanks for them so they can have a fulfilling social life.

HIPs to support peer-to-peer interactions. We model friendships. They will learn how to make friends and keep friends. How many of you have been in a situation in your lifetime where you would call a person, text a person, e-mail a person and they never ever reached out to you without you reaching out to them first. Anybody have that experience? Are they still your friend we're no.

Because what is a friendship? Is two-way street. Everyone wants to give and take. We don't always want to be the one making the plans, reaching out, asking them to want to be with us. We need to teach our kids that. They'll wait around for that person to reach out to them. We don't want that to not happen because they missed that incidental learning. Teaching them rules of friendship. Requiring direct communication for our kids. They need peers so they can directly communicate with. They need it. It is what it is but they need those opportunities. If they don't have it in educational setting find opportunities for it we need to have direct interactions. Much more meaningful and stick with them for a much longer time. Describe how to make and keep friends.

Let them know how a relationship is started and this is something that I still to this day

will talk to my daughter about. How are you doing at school. I'm fine. Are you going to do anything? No. What about your friends what are they doing. I don't have any friends. I said oh, tell me about your classes. Do you talk in your classes. I have a few people we meet up and walk class to class. Okay what is that.

Well, not really a friend. So you have to also determine from your child what is their definition of friendship. It may differ from yours. So you may think when they say I don't have any friends that they really don't have anything but their definition of friendship might be different. For her it has to be a meaningful, strong, committed relationship to consider it a friend, so we need to know if our kids are like that.

Popular kids at school consider their acquaintances friends, so they are that way with every similar person they know. So everyone thinks they are the number one person to that person. Do you have friends like that they come and say I love spending time with you. You are the best. You are wonderful and you overhear you say that to everyone else. Wait a minute. I thought I was wonderful. What's going on here?

We need to teach kids that happens. It's also someone that cares about other human beings but that kind of means you're important to her. Not the most important woman in the world to her, you heard her say it to other people. They don't automatically get it. It takes teaching. Provide interactions with deaf and hard-of-hearing peers. There are ways to do it in every state across in nation.

Get those interactions together with deaf and hard-of-hearings, the beauty of my involvement with hands and voices. My daughter has always been around deaf and hard-of-hearing adults. She knew this was going to be her future too. Deaf and hard-of-hearing role models, right? The famous people or people extremely successful or deaf and hard-of-hearing going into the same career path as she or he is. And with hearing

peers, the majority of people interact with a hearing individuals. So they need to know how to have interactions and relationships with them as well. Assume nothing and teach everything. If we overteach our kids we're going a really good job. There's no such thing as overteaching and making sure that they are getting access to everything that hearing kids and hearing individuals take for granted.

Teach everything, assume nothing. I am done and I have three minutes. Does anyone have questions. Grab the mic in case they do. Who wants to go first?

>> Do you feel there's a certain age group where you work on friendship and social skills more than other age groups.

>>ANDREA MARWAH: Good question, I think there's an age you have to be cognizant and that's around the 2 and 3-grade. When you have a child who is deaf and hard-of-hearing and especially those kids in general ed, so where are plans Torres made? Are they made once they're out on the playground. Made in the classroom. Do you think our kids are hearing that incidental chatter and incidental plan making going on? No. So here's what's a happening and I can tell you firsthand experience for asking me to observe my own child. This is going on and she's missing it all and she hadn't been taught she's missing it all. Everybody gets up a runs to the playground, she runs too and she stands and everybody takes off. What is her first thought? I guess they don't want to play we me.

Oftentimes, they turned around and looked at her and thought I guess she doesn't want to play with us. Know that it is happening and we need to tell our kids it is happening you need to find your person in the room who you can say what's going on at recess. You need to find that person. Otherwise you're the parent that's almost crying because I felt that my child had nobody. We missed the boat on that one. I hope you learned something today. I enjoyed having you here.

>> So I had a question about later ID kids when I see social pragmatic skills in appointments, what can I say to parents to bring it to their attention. Sometimes I can see there's a little bit of spice underneath the surface but they're reserved because of two personality types that emerge when kid wasn't IDDED until later they're really reserved and not attributing that to hearing loss but attributing to my kid is a shy kid.

>>ANDREA MARWAH: So in those instances and many other people more expert in education types of things but for me I would provide general information to the family and ensure betting tons and tons of events and activities, here's event you need to take them to, I think they'd love this event, but that I can them understand in general our kids deaf and hard-of-hearing may have difficulties with this and give them little bits of information. You don't want to bombard them.

We don't want to know the bad about our kidding, but sharing some concerns and seeing if they're seeing them at home. Nowadays are kids are like this. Are they socializing on that phone. That's real socialization these days. I hope I answered your question. Thank you for coming. Loved teaching all of you. Bye.

#### Demystifying iEHDI

(Captioner Standing By).

>> I'm Kelly Dundon. Sue Hannah is not with us. She's out on maternity leave. Just our standard disclaimer our opinions are the presenters and don't represent the official position of CDC. The data presented are provisional and not published. Some of our learning objectives. We'll go over what iEHDI stands for.

Early Hearing Detection & Intervention, participants be able to explain and identify opportunities to use iEHDI to promote health equity and identify how they can compile a complete and accurate iEHDI data set. This is de-identified individualized data submitted to

the EHDI program. This is under the CDC cooperative agreement this the states receive to help support their jurisdictional data systems and other testifies.

Currently there are 39 funded jurisdictions to funded cooperative agreement and there's 179 variables that are reported on each child depending on if they were referred from their screen, diagnosed in intervention and so on and so forth. So here are example iEHDI data variables that we're collecting. I see basic demographic, race ethnicity of infant and mom. Risk factors for the infant for hearing loss, their screening, their initial and final screening hearing results and resulted for left ear, location and provider if the jurisdiction collects that, diagnosis information, the test completed, degree, severity, was hearing loss identified, did they move out-of-state? If the child is identified as deaf and hard-of-hearing we have referral, enrollment status, exit date and other outcome data as far as other referrals that might have been made, if a hearing aids was fit cochlear implant and communication used in the home.

So historically the CDC has collected aggregated data with the hearing and screening follow-up survey. The survey has been around for the last 20 years that states report annually and give us aggregated data and the switch to individualized data came around 4 to 5 years. So some of the benefits that you can explore factors influencing the timeliness or which population more at risk for not seeking follow up.

Use the data to help guide efforts, data quality, some of the benefits of aggregated data you can generate routine reports for indicators and estimates or state and city, allows for screening facility and so on.

Some limitations of individualized so variations of data, definitions and standards among the jurisdiction. So we try too all use the same definitions and submit in a standardized way to use the data and disadvantage of aggregated data, inflexibility and how to examine relationships among variables and identify data quality issues and so on. So how does this

iEHDl data align with the HSFS, you look at births submitted in 2023, 36 statements here, three removed because of data quality. You see as a whole at national level, 36 level jurisdiction level, they line up fairly well as far as indicators of screen by one month, diagnose by three months and enroll in intervention. The iEHDl data the biggest difference at national level is enroll by six months. When you go state-by-state level there are more variances as far as over, under the screen by one month diagnosis by three months when you look at state-by-state level but at national level, or semi-national level they line up as far as iEHDl and HSFS. Here's if you prefer it in numerical format versus graph format. Your numerators and denominators are different as far as iEHDl data, but as a whole when you crunch the numbers to look at percentages he line up similarly. Know at injured level, not always the case, so happened that so many states above and below and averaged to come out with the same number.

So how complete are the data. Ms. Cory.

>> Sorry. Getting my notes aligned. So looking at completeness, why does when matter? So it's important in our data sets that we have high data quality and the data is complete. The goal of EHDl programs is going through that screening, and early intervention phase. So this can help identify infants that need the services. You don't need the socioeconomic status variables in that process but can help you target the different program interventions and in particular, as we note on this slide that loss to follow up population.

So, diving deeper into those iEHDl variables, as Kelly mentioned there are 179 that are reported in iEHDl data set but not all required. Tier 1 variables are required and Tier 2 variables are optional. That's the table I have up here to give you who Tier 1 and two variables are spread out. As you can see a lot of demographic variables are not required but again those are important in targeting your programmatic efforts. So over the next few slides they're

set up similarly, but we're looking at those 2021 births reported for iEHDI in May of 2023.

I'm breaking down this big buckets that we saw for the variables. So first if looking at infant demographics, the table on the left you'll see we have a column for the variable name and then we have known and unknown and what we have there is are we getting a known value for this variable or is it blank or unknown. So we have the raw numbers in the table but if you look at the graph we're showing it graphically so you can take quick insights. Known is in blue and unknown is in orange, the big takeaway all the way over to the right is chip enrollment status, so that is unknown for about 86% across all states and again we know you don't need this tortured your typical EHDI screening diagnosis intervention follow up piece but it could give you a hint of the socioeconomic status of these infants.

Looking at mother demographics, again set up the same way as last slide, we have a graph showing the different variables and numerically how many variables known versus unknown and quick glance so see which ones missing more on. In the middle see variables of marital status, wick status and payment type that we use for insurance variables. Those are what's missing more. These variables are powerful in looking at socioeconomic status and looking at analyzing your data from that health disparity point.

Mother demographics are fairly filled in. Looking at father demographics, these are Tier 2 variables and you see they're 50% filled in. Father demographics are not generally well studied and we know it's harder to get this information but again another way to help us provide insight into those populations.

Now, looking at risk factors, because there are so many we just decided to show it in graph form instead of table, but the main takeaway as we noted, blue is known and orange is unknown. You see all these risk factors in iEHDI data set are mostly unknown. Again a Tier 2 variable, so not required but knowing these risk factors can give you more insights into your

populations. I'm sorry that text might be really small. So if anybody wants to find me later I can show you those individual ones.

And then another one that we wanted to look at was provider locations. Again these are both Tier 2 variables but we do have-I did not move it -- thank you. For provider locations, these are Tier 2 variables but we do have the option in iEHDI for you to report the ZIP codes where an infant receives services. So looking at this graph we filtered down to those infants would did not pass hearing screening or referred to diagnostic evaluation since that's the population that would be going to a diagnostic provider. And overall as you can see I think it's about 20ish% for both where we have values for providers but it's mostly missing and again this is something where if you find gaps with different providers and different locations that's another great way to target program efforts. And I think I'll pass it over to Kirsten.

>>KIRSTEN COVERSTONE: Okay. Monday afternoon. So preparation of the iEHDI data. It can be overwhelming to be honest, but we recognize -- we being states the iEHDI jurisdictional programs recognize the importance. So talking about the complete data needed from multiple sources in many stays. I know in Minnesota we don't have everything in one system. We do pull from like vital records, for example, or the newborn screening program. Our long-term team pulls from education and so it's pulling all those different variables together to create this iEHDI data set.

Some of the data is routinely matched kind of behind the scenes from the system, but some of it does require some manual manipulation of it and that takes time and the timing of complete data from the different sources varies. For example our birth defects data -- or not birth defects, sorry-vital records come daily but education data comes annually so a big variation, and what happens in one state happens in one state and it varies between states significantly.

Data quality, also varies and again I'm giving an example of in Minnesota when there's free text in systems and you're having to find different ways to count that it lends to a lower data quality, so working to change free text pieces that you are routinely looking for into a standalone countable data variable is a work in progress. So this is just an example of a way to use iEHDI data to influence and guide your EHDI program, so one way -- I know Cory showed known and unknown, so one way that we did it is looking at some of those main categories and determining is it present in your system or is it not present?

That will give you a starting point of where to dive deeper to see different connections that you can make and knowing where your system is currently is really the first step and it might be painful to see but having knowledge to power. As I mentioned before, then working to increase those data variables is what you can do once you have the information available.

For us, combining the data from multiple sources outside of our EHDI IS is challenging and time consuming and requires everyone to do it and collaboration between the program to working to move those pieces that are currently manipulated outside the system into the IDIS is the focus.

So using iEHDI for QA, again improving that data quality. It will always be a work in progress. I feel like we can always do better, when we know more we do better. I mentioned the free text moving to a defined data field. Investigated differences between them HSFS, HSFS is aggregated report at that states send CDC. It's how we report EHDI data to CDC since 2007, I think, and the iEHDI is newer, so the HFST is that aggregated report. But each state can review their differences contacting Cory and Kelly and working with them and show you how to do it for your state and use that information going forward.

Constantly reviewing definitions as you make changes to your data system. Are the definitions you had in place still appropriate because definitions can change and we want to

make sure we're reporting what we think we're reporting. Collaborations, I cannot overstate the value of collaborating with other states that use your vendor or your system. You learn so much from each other and each state can share something they found that works or an issue they're having that another state has already figured out, so having consistent connections or meetings with other states is really important. Also collaborating with CDC. I feel like as their team has grown and are willing to work with each individual state to take them up on the offer to learn how to report or look at your data in order to evaluate it and evaluate your system.

I'm short on time. Kelly, if you want to....

I think I'm good, though.

(Laughter).

>> Good job.

>> So just our final slides so review everything we discussed, there are advantages to jurisdictions, submitting individualized data to CDC EHDI. We're honing in on data quality checks and how important to review HSFS because this data should be similar. They come at different time points but provide the same information. For jurisdictions that don't use iEHDI data set, or that don't use the iEHDI data set in conjunction with HSFS, we're interested this learning how your data is submitted. If you have insights about system mapping we're trying to understand those intricacies a little bit more. And as you can see there's work that needs to be done to improve data completeness and to conduct analyses on demographic and geographic factors so some of zip code data. So multiple sources that can be considered so a lot of states use rattle records for demographic data but other agencies can be considered or avenues could be Medicaid Part C, other child health programs or immunizations. So getting a little creative about where you can get a demographic data.

Next steps, so working collaboratively with CDC and your different EHDI jurisdictions

and we can do deeper dives into the iEHDI and HFST and people from the CDC team has a poster where she discusses this. She's done a deeper dive into those differences if interested in looking for your state. Our final closing note, Kirsten touched on this, having consistency definitions as well. Making sure you have aggregated HSFS data. Since Tier 1 variables are required looking into those further to see if there are gaps with your reporting and if you can get those variables. And then our bottom line to end it, quality data should be used to inform outreach to get our infants screened, diagnosed and linked to services. That is it. So we can open it up for questions now. I think we've got 2 and a half minutes.

>> I have 2 questions if there are required parameters that have to be reported and state don'ts out of the curiosity what happens when states don't report what they're supposed to? One at a time or both questions at the same time?

>> Is this on. I will say for that we're working with those states that are having data completeness issues on required elements to work with them on how to better capture that. Sometimes a matter if the information is there or how it's being extracted. I would say the states all who were applying said they had the data variables that were required. A matter of how complete they are.

>> You don't slap their hands or kick them out of their jobs.

>> We're a nice crew here.

>> The second question is no penalties or anything.

>> They all said when they applied they minimally collected it. Sometimes a matter if not complete how might be extracted in formats not compatible with iEHDI and working through challenges.

>> Thank you. My second question is why aren't risk factors required? I didn't realize they weren't. I'm not going to tell me staff can't collect the risk factors. Seems really important for

follow up.

>> Kirsten represents those conversations better. Risk factors is something a lot of states had trouble in the beginning. States are report it, but not complete on every single baby. Some is because they don't have a risk factor but nowhere for the iEHDI to create risk factors or getting risk factors from the blood spot card. That looks to us that it's incomplete but it might be complete but it's because there's an absence of information reported, because nothing to report.

>> States use awes, when you click on the risk factor link, you can set unknown, known, so it's there to say yes, known or unknown.

>> That's fantastic that you're able to collect that in every state. I don't recall other than I always knew it was challenging for states to collect on every baby.

>> Thank you.

>> Yeah.

>> I wanted to address your question, it's really hard to get the people that do the screenings to report the risk factors. Do they not just exactly what Kelly said, do they not report risk factors because there western any or because they didn't want to. Large part of the problem.

>> Hi, I'm Ellen from Rhode Island, just curious if you're planning to research out to states and start to look at the differences between HSFS what we call the iEHDI, the iEHDI data we submit to you is individual level and you're taking that and come up with these are your numbers. I've done some with sue HAN, why do you think this kid has a permanent hearing loss. We don't send you all the data we get. We send the first and last. Just curious about that.

>> Just moving up the food chain.

(Laughter).

>> So you'll probably hear me say this a million times during this conference, I'm the team lead for EHDI program and CDC. So I would say the data we receive is your data. I can't stress that more. I can't stress that more. So, yes, we collect the data and national level and trying to get these national numbers and feed that back to you. But part of the funding expectation is that you're also looking at your individual states data and doing similar things that we're doing. We're looking at HFSS. Not up to us at the CDC level alone to do that. It's a collaboration.

>> Right so my question is sort of like we wouldn't use our iEHDI file to do our data analysis.

>> Why not?

>> Because it's not as complete as what we have. It's different. It's not our full picture.

>> I mean it's very similar to what you might conclude or -- I'm curious if you're planning on looking at those discrepancies state-by-state.

>> I don't understand the question.

>> Okay. That's okay. I mean overall our goal is for each state to be able to analyze and look at their data so impactful for them. I know a lot of states don't have EHDI or figuring out Excel spreadsheet. What he use to pull these they'll share, so going forward. I mean are you talking about the timing of when the data is set as to when it's complete or not.

>> I don't know if it's different. It is a point in time, not a point that we would always necessarily choose. We don't in our state we don't care about the ZIP codes of places that people go. We know where they're going by the name of it. We're small enough to...

>> Doesn't it help you look at variables at that impact follow up.

>> Not so much in Rhode Island, but....

We're small.

>> Uh-huh.

>> Did that answer your question?

>> I feel like you have a question in there but I'm not sure...

>> I guess my question so are you going to say, hey Rhode Island, here's how many people we think in your state based on your iEHDI data and based on our programmers, you know, our whatever you use, this is how many people we think were diagnosed by three months of age. Is that the same as yours. You showed at the beginning not exactly the same.

>> So yes and no. So we did do a demonstration on last office hours. So we showed the difference between iEHDI and HSFS, we did that in DUA we said not going to go around and compare to everybody because this is the first time going iEHDI, right? So that's one way we have shared that.

We didn't share it with the individual states but we shared it at the broader level, and you're asking specifically at the individual state, I would have to think that through, one, we do have three epis doing the national level and we can't take on every state and do all the analyses for all of the states, but if you remember in your supplemental application for this year forward, we offered some additional money to work with the TA provider to do some analysis. So for those states that applied for that, we're going to help you do some of that, so, yes, and no.

(Laughter).

>> Okay, fair enough.

>> Okay. Thank you, all.

END TIME: 3:42 PM (MT)