

ROUGHLY EDITED COPY

NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT
Meaningful, Measurable Suggestions for Enhancing Family
Engagement in EHDI Programs: A Panel Discussion

SEPTEMBER 2, 2016, 11:45 A.M.

REMOTE CART PROVIDED BY:
ALTERNATIVE COMMUNICATION SERVICES, LLC
P.O. BOX 278
LOMBARD, IL 60148

This is being provided in a rough-draft format. Remote CART, Communication Access Realtime Translation, is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

>>> Captioner is standing by.
>>> If you are having a hard time with your audio, I encourage you to contact Daniel at 435-760-9049. And he will help you get connected to the audio. We will go ahead and get started in just a minute.

Okay, welcome to today's webinar. The title of today's webinar is meaningful measurable suggestions for enhancing family engagement in EHDI programs a panel discussion. This is -- and we were hosting today's webinar in addition to I want to recognize our funders from the maternal child and health bureau for the health resources and services administration. The authors that are presenting today are responsible for their views and their content and there is no specific endorsement by HRSA and NCHAM. I will turn it over to Janet who will be the moderator for today's call or webinar. Janet go ahead and take it away.
>> Good morning, everybody.
This is Janet.
I would like to thank you for joining us today.

I know in everybody's busy schedule we thank you for carving out a piece of time to ponder, think about, learn and think about your own state system and family engagement.

Probably now more than any other time in the history of our EHDI system development the focus on education is on the forefront. As a parent myself, I have a daughter who grew up deaf, hard-of-hearing and I'm also the director for hands and voices headquarters.

We have a chapter 52 chapters in the U.S. and Canada.

We were pleased that our panelists could join us here today.

We are going to be exploring the partnership between the professionals and parents in the development of EHDI systems. Patiences with their own child, the information and resources they need in their own journey.

Also the next level of parent-to-parent support, how families support one another and then, of course, the other level would be family engagement and leadership and representation in the systems that serve us.

All of these three levels are intertwined.

In fact, I think about the first time as a mom I was driving to a meeting to give my input as a systems -- in a systems meeting.

I remember thinking to myself, what do I have to contribute?

I only have my story and my daughter's journey.

And yet that was the foundation for obviously many years to come of being able to stand not only for our own family's story but that of others.

With that being said, we have three states represented today.

Panelists who are sharing their own experiences.

I will let each of the panelists introduce themselves.

We will start with Colorado.

You can move the next slide to the next slide.

I'm going to go ahead and turn it over to our Colorado representatives today.

And by the way, at the end of these three brief presentations, we will be opening up the conversation for questions from the audience.

>> This is Erica McKiever.

I will go ahead and get started because if we get the next slide with our start of our presentation, we have our pictures up.

On my screen I'm not seeing the next slide.

>> It should be the Colorado EHDI systems.

>> I will keep going.

I don't see it on my side.

>> I don't either.

>> Okay, go ahead and I --

>> Okay, my name is Erica McKiever and I work for the Colorado Department of Public health and I'm the newborn hearing program supervisor.

I have been with the EHDI and newborn hearing program for six years now -- program for six years now and working as the program supervisor for four years and I will let Vicki take it from there.

>> Hi, I'm Vicki Thomson and I serve as EHDI coordinator for over 20 years and currently I'm the lead investigator of the HRSA, EHDI grant.

I had the privileges of working with hands and voices since 1996 and before that I diagnoses Janet's daughter.

Janet and Sarah have been an integral part of not only my live but the whole EHDI system.

We are very lucky.

>> Hi, everyone.

I'm Sara Kennedy.

I've been the director of the Colorado chapter for the last five years.

And worked with Vicki very long time.

And I am the parent of a high school student who is doing a transition year after graduation, if you can see her picture which I can't see quite yet.

But moving on --

>> I apologize.

I'm working on fixing the slides.

It looks like that everyone can advance the slides on their own which is unusual.

I'm going to fix that but you can advance the slides on your own.

>> Okay.

So this is Erica so I will start off our little talk by first saying that our -- the three of us especially, we fine ourselves talking to each other a lot.

We have each other's cell phone numbers, we are really good at texting and Sara even lives in Colorado Springs and Vicki and I are on two completely opposite sides of Denver.

We make a big effort to always be in contact with each other whether it be through in some conference calling or checking in with each other on texting.

We even found a really nice middle point that we have some nice meeting space to be together with some technology tools in front of us.

We have a lot of success in communicating through those different ways.

And so I'm going to talk really briefly about our system in Colorado that maybe many of you know already and many states are functioning similarly is that we consider ourselves a two-stage screening state so we recommend in Colorado that after the initial screen not pass, then there be a rescreen. So again typically -- like typical to many other states as a rescreen one to two weeks after. And then if there is not pass associated with that screen, the recommendation is then that child has a full audiology evaluation at that point.

If the child is identified as either bilateral or unilateral hearing loss, we have a process or a system in place. It's actually integrated into our data application to where not necessarily a referral, but a notification can be sent to our part C co-hear or Colorado resource hearing coordinator through CHIP if you see that slide, the yellow box is where that's mentioned.

And so I won't go in to what all they do just for sake of time, but audiologists make that official referral for the family to the CHIP program.

What we have in place, though, is to help audiologists, we were trying to streamline our process and then what happens with the CHIP providers is that they are tasked with making sure that the parents are aware of and get a referral to hands and voices. And of course this talks about our children ages 0-3, but yet hands and voices obviously provide services through age 21. And so on the bottom there is a little list of -- it's titled local EHDI teams.

What that means for us is that we have a system in place where we really oftentimes will hold meetings usually at a hospital so this could be like a regional-type situation where hospitals like to have these teams come in to visit so the hospital is part of the team, too, but we always try to have this list of representatives available as we can.

It's oftentimes very difficult to get everybody there at the same time.

But we have a parent guide from hands and voices, sometimes even a parent guide and maybe Sara can go.

We have the hospital coordinator which is the person we refer to at each hospital who is managing the system there and then audiology regional coordinators help us be our eyes and ears and arms and legs out in other regions that makes it difficult for us to get to.

And then co-hear which is the intervention provider coordinator

for the area will be there.

And we put PCP here that is a dream and that is -- it is very difficult to get PCPs there.

That's our key.

We hole these as needed.

We try to get out on somewhat of a schedule to the different regions and hospitals and we all coordinate.

Honestly, I would say that probably mostly me and Sara who tend to get those organized and get them running.

We have about 65,000 births a year in Colorado.

Each year we average about 150 confirmed hearing loss identifications.

And then hands and voices, Sara will talk a little bit about some of the activities that we do here, but just some numbers. They do -- they are engaged with about 120 families a year and for about 85 of those they offer home visits and welcome bags. And Sara can talk about that that's our system briefly.

>> And this is Vicki and I will talk about the road map.

This has been one of the highlights that hands and voices has really put in the forefront in our system.

We have this customized for every hospital in the state and now some the birthing centers and mid-wives.

And on the back there is a resource list of where they should go next.

Where is the nearest audiologist.

What we plan to do in the future is to actually have audiologists go into EHDI so we aren't highlighting one audiologist or two audiologists but actually allowing families to see which audiologists can meet their needs and where they live closest.

This is the road map for families and Sara does a wonderful job of trying to keep it updated when there are changes and communities and hospitals.

>> This is Sara.

I wanted to add about the road map that's also an interactive site on our website.

So families are increasingly finding us through just a Google search about what do I do when my child is identified with a hearing loss?

If you scroll over each one of these sections, there is information about screening results and what kind of testing is done and a link to the lost and found videos that families can see about the importance of returning for a second screening, for example.

Moving on to the next slide, have been working with the EHDI system since my own daughter was three years. She was late identified and missed the hearing screen with the midwife home birth.

I joined my county's local committee and my midwife joined and we began collecting feedback from families about having the screening and early intervention screenings went to be able to inform our local group about how to make things work more smoothly for families.

As Erica said, today we meet about 85 families a year who have been recently identified primarily referred by the co-hear coordinators but also by audiologists and home interventionists and as I said quite a few families find us on their own.

We focus on providing emotional parent-to-parent support as well as educating parents about their child's hearing loss and the supports available in their region, educating them about the whole process that they now find themselves in and then the transition from part.

Their local providers and questions that they have and connecting them with other parents, sharing the similar journey. As Erica said, we continue to provide support through age 21 but I know that's not the case in every state.

Our guide staff has both regional guides and specialty guides. There could be guide who has a guide with microtia, a Spanish speaking guide who does support in Spanish for families and translates materials for us and we have a guide who has a child attending our state school so she is a great resource for families all around the state interested in possibly sending their child to our Colorado School for the Deaf and the blind. Our chapter board is also comprised of 50% parents of kids who have hearing loss so we definitely value that parent's voice in helping us design support for families.

As a staff, we bring the face of the baby with CMV or who has been late identified or who has a progressive loss or the military family who is just moved into the state.

Or the single teen mom who has her own story to our decision tables such as the state health department lean event or input into our work plan bringing that story forward to help us make a smoother service plan for all of our families.

And lately we have been attending the pediatrics hospitals. We have 13 of those hospitals where pediatrics as a for profit company is providing hearing screening and we have been providing in-services to those screeners and the nurses on the

maternity floor.

It's been well received.

The screeners have no idea what happens to a baby after the referral.

>> Sara, one minute.

>> One minute, okay, let's go forward to the next slide.

This is just a picture of some of our projects.

The middle picture is deaf, hard-of-hearing mentor project.

We call it the partner project that started in 2013.

We've had great support for growing and look forward to doing work.

Checking families with mentors who are deaf or hard-of-hearing themselves.

There are some of our events.

There is the mom's night in picture.

And there is flier from a pragmatic language workshop which was well attended last year and our Spanish speaking group is growing greatly and we have our own Facebook page for those folks directly in Spanish.

Some ideas for the future.

We have -- we are dependent on referrals but we are looking at the possibility of having an opt out for families who be able to say I don't want contact otherwise I will get contact from hands and voices.

We were looking at parent guides for follow-up coordinators for families who have missed a screening.

On that last slide I wanted to give you a sense of where we are going.

Hands and voices headquarters through the guide by your side program is looking at this model that you see on the screen there on how we can bring a learning parent the resources that they need to become a supporting parent.

So to look at ideas of knowledge impacting well being and empowerment and all of the areas that a family has to keep some level of competency to be able to advocate for their child and navigate the system.

And there!

>> Thank you very much.

I know we will be really hard pressed for time and these slides will be available.

Alyson will let us know how the slide presentation will be available at the end of this next we will turn it over to the Louisiana system.

Go ahead, Louisiana.

>> Hi, I'm Terri Ibieta.

The Louisiana EHDI program manager and I have worked with the EHDI program in some capacity since 2002.

I come from a background of bag teacher of the deaf, working with families of newly identified deaf and hard-of-hearing children.

>> Hi I'm Jill Guidry.

I'm a parent of a child with hearing loss.

I'm the director of the local chapter ever hands and voices and also a parent guide.

Okay, Terri.

>> In Louisiana, we have approximately 64,000 births each year.

Our screening rate is almost 99%.

Our referral rate stays around 5%.

And so far in 2015 we have 75 babies who are identified with permanent hearing loss.

Unfortunately not all are identified by six months so this number will continue to grow.

The EHDI program has had a parent on staff since 1996.

That's as far back as my knowledge goes.

I know at that time there was one parent part time parent liaison.

In 2004 the Louisiana hands and voices chapter was initiated.

It dwindled after Hurricane Katrina in 2005, and our chapter had been active since 2007.

In 2012, the EHDI program hosted a guide by your side training and we began hiring parent guides.

This year we hosted an ASTra advocacy training and we hired a lead advocate and initiated the ASTra advocacy.

Currently we have seven part time parent guides which are equivalent to two full-time positions.

Louisiana has always had parents involved in EHDI.

We started out with one and now there are seven.

Maybe because of my early intervention background, the thought of parent involvement in EHDI just came naturally.

Also in Louisiana we are fortunate that our EHDI team consists of three deaf educator, two audiologists, and an epidemiologist.

When I worked with families of the -- lieu the Louisiana home intervention program, families would always ask, do you know any other parents whose babies are deaf or hard-of-hearing?

I always connected one parent to another parent long before Louisiana had hands and voices or guide on your side.

I felt as professional working with families, I developed some awesome close relationships with parents.

For some I would become a member of the family.

But the one thing I could never share is what it was like to walk in their shoes.

>> Our EHDI values our parent perspective and it has a direct impact on all aspects of the E H-DI program.

Not just in direct parent to parent support.

I can think of many times when one or two of our EHDI team members is working on something and one of us will say, hmm, I don't know.

We need to get the parents to look at this.

Or, ahh, we need to see what the parents think about this.

One of my big pet peeves is when one of our parents provides their input or gives their opinion and then says, but I'm just a parent.

There are so many things that parents know better than any professional ever could know.

Every health program uses a consumer model and EHDI, the consumer is the family.

We have two parents with members of our advisory council and two members of our EHDI team serve on the guide by your side advisory board.

Our parents are part of our team.

Off the within the parents taking the leadership role.

I remember when we created letters that would be sent to families of babies that were lost to follow-up, we wrote a draft of the letter with all of the facts that needed to be included. And then our parents helped us to word the letters so that parents receiving the letters would clearly understand what they had to do, why it was so important and who to contact if they needed help.

One of the benefits of having parents involved in all aspects of our program is that their passion is contagious.

Sometimes as program coordinator I get overwhelmed with the bureaucracy, with the red tape.

Then one of the parents will come to my-- will come to my desk to discuss something with me and I'm brought back to what EHDI is all about.

Our parents and professionals have a mutual respect.

We learn from one another.

Our knowledge and understanding of each other's perspectives is always expanding.

Our relationships are continually growing, we are a team.

We never --

>> I'm sorry, a few minutes.

Three minutes.

Thanks.

>> Three minutes left.

>> Okay.

We are a team.

We never refer to ourselves as EHDI staff.

We always say our EHDI team.

Now Jill will discuss some of the specific activities that we are currently working on and activities that we have planned for the future.

>> With parent to parent support in Louisiana every child with a hearing loss is immediately referred to a parent guide.

The guide contacts them and supports them through their journey.

They also engage in activities in the community, hands and voices, host activities.

They receive newsletters and are invited to annual parent training.

With follow-up activities, parents are on our EHDI team call families to make sure they understand the referral information and the importance of timely retesting.

And another thing we do is send letters to the family, faxes to physician offices and if a child is lost to follow-up, we even call the family.

We are doing much more than just sending letters, faxes and making phone calls.

We are finding babies who may have a hearing loss and helping to ensure that parents know the importance of returning for follow-up testing.

Parents totally get it.

They know first hand the difference when a baby is identified early versus when a baby is identified late because follow-up didn't happen.

We get upset and take it personally when we receive a report from an audiologist when a family who has been identified late. The first thing we usually ask is, did they fail their newborn hearing screening if so we want to know why they were identified so late.

Throughout the process we are engaged continually with our EHDI team, getting feedback and if necessary revamping strategies to quality improvement to ensure the effectiveness of our work.

We have been sifted and improving through collaboration, the outcomes have been with parent assistance the loss to follow up from 39% in 2009 to 29% in 2015.

Training.

Parents receive training and give training in addition to annual trainings provided to parents, our parents also assist in providing training.

With pediatrician offices, a parent in one of our EHDI staff will go to one of our pediatrician offices will provide training on helping the staff to understand testing and what to do once a child is identified.

Once the staff member knows there is a parent of a child with hearing loss, then they get it.

This is why it's so important.

We also provide input through advisory council meetings.

As parents we are keenly aware of how and why it all fits together.

Speaking at pediatric Potpourri events, our chapter champion leads off.

It's when the parent speaks that it all seems to come together that essential element that we have to ensure the families will follow-up.

As far as future events we are looking at coming to Louisiana. Looking to provide training to parent guides first and then to families.

Regarding the IIFP, parents need to be involved in assisting families with newly identified babies through the process.

Increase in collaboration between our parent guides and audiologist and parent guides and PPP.

For an integral part of the team.

We know it and our EHDI team knows it as well.

Thank you.

>> Thank you, Jill.

Thank you Louisiana.

As a presenter myself I'm beginning to have more appreciation for moderators.

I know we were pushing our time limits here there are such good information here so we will go ahead and move on to Wyoming and then we will open it up for questions from the audience.

Wyoming, take it away.

>> Great, thank you.

So my name is Bradley.

I'm here with Jackie and we were at the Wyoming EHDI program.

I want Wendy to give just a brief introduction of herself if Wendy you are there.

>> My name is Wendy Hewitt.

I am the mom of a boy and a daughter that were both born with profound hearing loss.

They are 14 and 12 now.

And we started a Wyoming chapter of hands and voices in May of 2006.

With the help of EHDI and our deaf and hard-of-hearing outreach team, we were able to get a good start with hands and voices and made a lot of progress.

>> And I'm going to kind of go fast through our things here just so we can -- we have a bunch of ideas that we want to just kind of share for brain storming.

I will say that in Wyoming we have a two tiered screening system in the hospital using AABR and then beyond the hospital we also work very closely with child development centers in the state to identify late onset hearing loss.

And we have a couple of slides here of our philosophy regarding engagement with parents.

And the families of children who are identified with hearing loss.

But I will just say that we believe parents are the most effective teachers, friends, advocates and support sources for other parents.

So what we have tried to do is -- and we love working with the parents with Wendy and Kim is another person in the state.

We have -- we just gotten lucky we have a great working relationship with them.

But we try to involve parents and could you go to the next slide.

We try to engage with parents at every level of the 1-3-6 system.

Here what we have done is kind of give an litany of things that we along with hands and voices do at each one of these stages.

I will say that although we think these things are very meaningful and they have been very helpful to the state, we are not so great at measuring them.

So that's something we are definitely trying to do going forward, but yet we think these things are important but as far as measuring their effectiveness, that we are working on ourselves.

We provide when baby fails an initial screening in the hospital but we have a letter that's given to the parents in order to kind of encourage them to come back for their rescreening appointments.

Of course, our follow-up coordinator communicates with baby's primary care physician.

We also kind of have direct kind of -- we try to directly engage with parents in the hospital by providing information about the

hearing screening for the families.

We have a little T-shirt that we give them and the parents get a post card with the hearing screening results on it.

Then more recently we have been working with Kim Reimann who was a hands and voice -- she is a Hands & Voices member on working to educate the physicians regarding the importance of -- in the state.

When it comes to the three of the 1-3-6, Kim Reimann is our specialty clinic coordinator.

So we have some issues with getting securing good pediatric audiology in the state, about once every six weeks we set up a clinic and Kim is in charge of organizing that clinic.

We have used a letter as far as getting the diagnosis by three months of age, we used a letter for a child who is successful who is diagnosed with hearing loss who has now been very successful team.

We have a letter that has been penned by her to parents of newly identified children.

Maybe go to the six, please.

And then we also when it comes to early intervention in the state, we have a pediatric speech language pathologist who really connects with families.

Will join via face time with an early intervention provider and the family there to LENA analysis as well as NECAPs so participate and help the family engage in the shared reading program through the Colorado schools of deaf and the blind. As well as some other sign language programs and we hope to use this person to start connecting with Utah State University for some early intervention services and then kind of have to try to start measuring how effective these things are or how helpful they are to parents.

We are serving parents.

And so some other ways that we have just been collaborating with Hands & Voices, we do try to help them with their personnel costs.

We have been working together since Wendy mentioned since 2006 I believe so that's over ten years.

And we have also been trying to work together more recently to do quality improvement things throughout the state to engage with primary care providers and also to improve the quality of prevention in the state.

I think we have one more.

Okay, and then this is just kind of something we are thinking about going forward is to have parents and Hands & Voices visit with audiologists in Wyoming who see kids under the age of five

to kind of help them produce reports that are good for or easily understandable by parents and early intervention providers and also the -- soon encourage them to report to the EHDI program as soon as possible.

And do this from a parent's perspective.

Okay, I hope I left good time for questions.

>> I think we will take questions in just a minute.

Wendy, did you want to add anything?

>> I don't think so.

We just have had a good relationship and always helped with funding different parents and the funding for -- from the start they helped us with personnel funding and things like that and we just have a really good relationship.

Kim is on our board and working at the pediatric clinic.

She has helped to get those younger kids to us quickly.

We do not have a GB or a guide by your side in our state just because of the small numbers that are identified yearly and the -- the size of Wyoming, how spread out we are.

And it has helped to get the younger kids to us having her work there.

>> This is Janet, I think Wyoming is a great example of a state chapter that does not have a guide by your side program and maintains the critical elements of parent-to-parent support.

We know not every chapter has that official program.

Thank you so much, panelists.

I want to point out I love that Wyoming has a written philosophy of parent engagement that is really beautiful.

You don't often see things actual in writing in the very active writing down that philosophy.

I think it's really wonderful.

I love that Colorado uses an evidence based model, that very last slide of the structural frame with for parent-to-parent support and they use that as a basis for some of the work that they are doing in Colorado and for Louisiana, I was impressed not only what you do together but who you are together in terms of that culture cultivating the culture of respect.

We know that here on the call today are many representatives, both on the parent side and the systems side of both successes and challenges in your state systems of this.

And so we want to acknowledge there are many of you out there who are also doing really good work in this area.

So we are now going to open up for question and answers.

You can type your questions into the tech box -- text box and we will read them out loud and ask the panelists to respond.

So we are waiting for our first question.

We will take questions or comments.

I'm going to type them into the box.

The first question is I heard that the PowerPoint will be available can we also get a written transcript?

>> Can you answer that question?

>> Yes.

So we will have both the PowerPoint and the transcript ready in about a week.

Look for an e-mail letting you know that both are posted on the website.

>> While we are waiting for questions, Alyson, did you get the slides for resources if we don't have it here today on the deck, we have a list of resources that are -- we put together in terms of ideas, definitions of, more thorough in-depth look at family engagement.

So we will make sure that's included when we disseminate the PowerPoint slides.

The question is, how does Louisiana keep guides trained and engaged and how are they funded?

Jill, you want to take that question?

>> Sure.

We in Louisiana keep our guides trained by having annual trainings.

We do meet face to face at least once a year.

In addition to that, we do conference calls every three to four weeks where we are able to have a collaborate and share information about working with families, questions and things like that that come up.

But then also each time that one of us presents at a different type of event whether it's our annual deaf summit that's held in Louisiana, one of us presents there and that's another learning opportunity.

But we do have our face-to-face annual guide by your side training.

And Terri?

>> Currently our parent guides are paid through the EHDI program.

>> Great.

Thank you.

The next question is how does Wyoming send out post cards with results and stay HIPPA compliant?

>> Sure.

This is Bradley from Wyoming.

What we do is we have post cards that we print and send to the

hospitals so they have a supply of them and then the hearing screening results come directly off the little sticker that goes on to the post card and the parents take it home from there. That's how we go about that.

We don't have anything through the mail.

>> There is another question asking again about the copy of the PowerPoint materials.

Yes, absolutely.

And they love the Colorado created -- I love how the Colorado created their road map.

You can find the interactive road map on the Colorado Hands & Voices.org website.

I don't know Sara did you want to add anything about that?

>> That's true.

www.cohandsandvoices.org.

>> The next question, what is or are the biggest barriers to increased family engagement in state EHDI programs and systems? I will let any of the panelists reply who want to.

>> This is Vicki and I will say we haven't had many barriers at all, but I do know that Sara has occasionally had trouble finding a perfect guide.

For example, we are really struggling to find a Spanish speaking guide for a Spanish speaking family.

So it's sometimes just being able to find the right kind of parent guide to fit with what our needs are at the time.

>> In Louisiana also, we have trouble finding the right parent guide to fit two things.

One to make sure that they are geographically spread throughout the state and the other is the specific parent guide.

We are fortunate we have a Spanish speaking parent guide.

One of our needs is to have a parent guide of a child with unilateral hearing loss.

>> Any other comments around this question?

>> This is Sara in Colorado.

I would also say just on a practical basis for states looking at increasing family engagements, parents work and to be present at some of these things I think we can expect to pay them for their time.

They are having child care and leaving work possibly.

So something to consider.

>> Thank you.

The next question is do you have any metrics for how quickly the guides will contact families with newly identified kiddos?

I think each program may be different, but in other words what is your time frame for when you get a referral to contacting

that family?

Could each state reply?

Sara, why don't you go first.

>> Sure in our state we expect the guides contact the family within 72 hours and that could be a phone calls an e-mail or however the family asks that they be contacted.

That doesn't mean there is necessarily been contact back but we have made an attempt.

>> Thank you, Louisiana?

>> This is Jill in Louisiana.

We have our guides contact families within the first seven days of receiving that referral.

If we are unable to contact them by phone, we try by text and if we are unable to receive or establish contact, we do send a post card to try and get our foot in the door that way as well.

>> Thank you.

Wyoming?

>> When did you know for certain what our time line is?

>> Once we get -- because we don't have the guide by your side we don't actually go in and do home visits.

Once we receive their contact information, we try to get a phone call out to them within a couple of days.

>> Thank you.

Here is a question.

We have heard that deaf mentor programs are evidence based and that children who have mild or moderate hearing loss benefit from being mentored by individuals with very different and more profound hearing loss.

Do you know what research that is that has demonstrated this?

>> This is Sara.

That is a terrific question.

I can't think of research off the bat but maybe we can get back to you after the call.

We know from research that 30% of children with those mild to moderate losses do progress in hearing loss so that's something to consider.

>> Any other comments about that question?

Next question, question for Louisiana.

How are you able to give child names to non-DOH staff such as Hands & Voices?

This is considered protected confidential information in our state and will limit our ability to.

Ment the model but would like to understand how you are able to accomplish this.

I think this is a great question probably for all of the states

but Louisiana?

>> In Louisiana our parent guides are part of our EHDI staff so we don't really give the referral to Hands & Voices.

They are part of our staff.

They are part of our team.

>> Great.

Colorado, would you answer that question as well?

>> We do have a memo of understanding between agencies and our referrals typically come from the part C of the early intervention and we have an agreement with them, a signed release as well.

>> And this is Vicki.

This next year what we hope to do is have an MOU between the University of Colorado Denver which holds the EHDI grant and the Department of Public help and see if that's how we can have our Hands & Voices parent guide contact families for resources and information if they haven't followed up.

>> Thank you.

Wyoming did you have an answer to this question?

>> Go ahead, Wendy.

>> That's fine.

>> I was going to say the parent has to sign something or give -- like at the clinic they have to give Kim permission or fill out our membership form while they are there with Kim before we can contact them.

>> We have a signed release for sure.

>> I can say -- this is Janet.

I can say across the nation it looks different in different ways with different kinds of contracts or MOUs and both opt in programs as was mentioned here with families signing a release to opt out where it's constructed in and part of the system for that information to flow.

Here is another question.

A comment and then a question.

I think that EHDI coordinator from Louisiana spoke eloquently about why parents are involved in EHDI.

Thank you so much for getting the transcript.

It will be helpful and can we get permission to use this in our material?

>> So I think the answer is yes, you can get permission.

I would say if there is specific items in the PowerPoints just go ahead and contact Alyson and we will see that.

I'm sure all of the states will be willing to share the information.

>> I have a further suggestion.

This is Alyson, is asking the panelists to post all of their materials on the virtual learning collaborative so everybody can have access to it and then we will also make sure if you don't have access that they can contact me and get access.

So everything can be posted and shared if states are willing.

>> The next question is a wonderful question.

How do you suggest measuring family engagement?

You have recommended matrix for the measuring the effectiveness of family support.

And before I turn it over to the panelists and talk about how they do it in their states, I will say there is some in the resources that we will be delivering there is some good guidelines in a broad sense of family engagement from an NCHAM family engagement.

Some materials.

So we will ensure that we get those resources to you.

I know Wyoming has done some work in measuring their effectiveness through quality improvement initiatives and maybe other ways as well.

Let's start with Wyoming.

How do you measure the effectiveness of family engagement?

>> This is Brad.

Sorry, you hear me?

>> Go ahead.

>> Sorry.

This is Bradley some this is where we struggle I think the most. What we have tried to do is gauge what the family's thoughts are on some of these things that we are trying to help them with and also probably what we had the best success at doing so far is just keeping track of our 1-3-6 numbers over time and seeing if the activities that we are doing are having a positive effect on those numbers or if they are having no effect.

Is that something that is difficult for us.

>> Thank you.

And either the other states want to comment?

>> This is Vicki.

We occasionally do parent survey just to see how much they learn from their parent guides and from different parts of the EHDI system.

That's how we are currently measuring that.

Do you have anything to add to that, Sara?

>> We are looking forward to the results from the NECAP survey that's going out next week to get information currently.

We haven't dawn survey for a couple of years and knew that was coming out so we waited.

>> Great.

>> In Louisiana we have also done parent surveys and we do also have activities planned to improve that in the future as we all know it's difficult to get information back when you send out surveys.

>> This is Janet, I would like to add a couple of concepts. Really basically you can track family engagement by the number of families engaged, the amount of funding allocated to family engagement and I can tell you that at hands and voices headquarters we are working on a metric of impact of family-to-family support at the level of outcomes of families and their children so not just looking at the satisfaction of that but how parent-to-parent support actually impacts the outcomes of families and their kids at different levels and we are using the evidence based structural frame with for that. That will be ready probably next year at some point.

It's a great question because we always are looking at ways to measure the effectiveness of these things.

And I would go back to looking at the quality improvement model for being able to measure when you are testing out an activity in your state to see what the outcomes are through the small measures and small tests of change of I think quality improvement is a great way to begin to measure that.

>> So this is Alyson, if I can add a little bit.

As Bradley mentioned this is an area that's been challenging in the past and they have been working really hard on figuring out new metrics to be able to measure family engagement.

So they are moving to some of those components that you were mentioning before.

Like not just necessarily events held and things like that, but even looking at both qualitative and quantitative information about how often the parents are contacted by somebody from hands and voices and some of that qualitative information about what goes on during the conversation, how the parent guide is -- like what resources are providing, et cetera.

So they really are trying to get creative on new ways to measure engagement and what some of those outcomes would look like.

I think this is an exciting conversation right now and we will continue to be for the next year or more.

I just wanted to add that.

>> Absolutely.

Thank you.

While we are waiting for additional questions, I can tell you Hands & Voices went back through the current round of EHDI grants and began to pull out from what was posted on infant

hearing.org different ways each state system has worked at family engagement and family-to-family support in their EHDI systems and it was a really interesting process just like every element of the EHDI system in any individual state or territory system.

The levels at which certain states are at vary from you may be sitting there still at the relational stage of trying to build those relationships between one another all the way to really amazingly having integrated family engagement as your primary not only just value but funding utilizing families in your system to this day.

And so it's just a really -- we are sitting in an exciting time, I think in terms of the levels of family engagement and family support here in our systems.

Here is one more question before we close.

For those that have guide programs supported by EHDI, how many have direct referral once there is confirmed hearing loss and do any use the road map after diagnosis?

So this question would be for Colorado and Louisiana.

>> This is Sara -- oh, go ahead.

>> Go ahead, Sara.

>> In Colorado we have referrals from primarily the early intervention programs so it's not a direct referral from EHDI as Vicki had said.

That's something we are working on for the future to be able to have.

If we use the road map after diagnosis we refer to it as a resource.

We want families to understand the 1-3-6 system and all of the players and what happens so that they can be an educator for other families as well.

In this community that's how we meet each other we use it in that way.

We are looking at qualitative items like does the family, can they explain their child's hearing loss.

Can they explain why a pediatric audiologist is necessary.

Some of those basic foundations of knowledge that are necessary.

I will let Louisiana talk.

>> As we had mentioned, they are -- the parent guides do receive a direct referral when EHDI is notified that a child has a permanent hearing loss.

We are not currently using the road map in Louisiana.

We have used it in the past and we are in the process revising and improving our road map so we can use it again.

>> This is Erica in Colorado.

I will add to that, so we had added a data field into our data application that gave the interventionist an opportunity to put in a date of referral to Hands & Voices.

So I think the definition of referral can be different for some. It could be one where a name is given to another entity as a referral, or some awareness of information being given to the families.

So what we were trying to do was have this field in there so we can have some kind of tracking mechanism to know how many families were being informed of the services that they could be getting.

I will tell you honestly it didn't get populated very well from the data entry perspective and so one thing we are looking at what we sort of evaluating just even the design of our data application, we looked to see where it was at and it was in sort of another tab.

So I believe in the out of sight, out of mind.

So we have plans to move that data field on to the main screen that interventionists are typically entering data.

This way it answers the previous question about tracking at least for referral.

And our hopes are also to where we have the ability to use a data field in the same section where interventionists can work together to identify the families that are getting the services. And hands and voices has their own tracking for that, too.

>> This is Janet.

I would like to thank all of our panelists here today for your wonderful presentations for your ongoing commitment and dedication for working as partners together to ensure the success of our families that are moving through this system. I'm going to turn it back now over to our host at NCHAM for final comments.

>> Thank you, Janet.

So I do want to remind everyone that the webinar and transcripts will be posted on the website by a week from today so that's September 9.

And we will make sure that you get an e-mail notification when they are posted.

I know that there are a lot of questions that we did not get to so what I would like to offer is that I will copy all of these questions and provide them to the panelists who have joined us today and give them an opportunity to do a text response and include that in the information that we post on the infanthearing.org website because I think that there is a lot of really fantastic questions and I want to make sure that you get

an opportunity to actually ask those.

I also see that Michelle from MCHB has provided resources regarding deaf mentors.

So I want to make sure that you have those resources as well.

And that will -- with that we will conclude our webinar for today.

We appreciate your attendance and have a great afternoon.

>> Thank you.