>> Hello, all of us will be speaking to I'll let people introduce themselves as they go along, I'm the EHDI coordinator for Arizona but for this project I worked for Illinois. So we'll talk about the PEP project and how it can be useful in what you do. And PEP is an acronym for Promoting EHDI Practices. The first person up will be Keirsten, she's almost ready, she'll be up to talk about JCIH. She's been on JCIH a co-chair for the last couple years is that true? JCIH is the Joint Committee on Infant Hearing. And it is the been established many years and that's what we use as our goaled standard in Arizona for what we choose to do. And propose.

>> Turning it on helps. Okay. So this happened to me the last time, I don't have any my notes so you have to bear with me, JCIH was established in 1969. And has representation from 7 different organizations, oto laryngology, audiology, pediatrics, nursing and it expanded. But the focus is on early identification. Sorry. And hearing screening. Okay.

Sorry, all right. Next slide. Thank you. Yes , all right. There's the organizations represented currently. You'll see AG-bell. The [off microphone] which ends up being the coordinator but the American academy of pediatrics, of oto laryngology, head and in neck surgery, ASHA [listing]

So next slide. So the primary function of the JCIH has been position statements from the beginning. So the very first position statement in was one page and four paragraphs and it acknowledged the need to detect hearing loss early in life but acknowledged mass screening could not be justified at the time because there wasn't appropriate test procedures. And it encouraged research.

So it was, you know, the initial statement, four paragraphs. The statements that followed really 1973, they delineated the first high risk factors and really the following sequential statements would build on those risk factors. In the late 80s, early 90s, it brought the recognition of technologies. And then the comprehensive peer reviewed 2000 position statement promoted not only universal screening but a quality system of care for early detection and intervention. I think there's the image.

So from the first statement of four paragraphs, to the most recent 2019 statement, 44 pages, each statement has become more explicit in its recommendations for detecting and monitoring infants with suspected hearing differences.

If you are not familiar with our website, that QR code will take you there. You have access to all of the position statements. We also have frequently asked question documents on there. The website will be going through the an update that is a priority that the committee made this year of getting that updated. And then currently, the committee decided because it took so long for the last statement and it's gotten so big we are working on smaller, more topic-focused documents. For example, risk factors and late identified hearing loss.

So those are the two I guess biggest things that we're working on right now. The hope was that the turn around time would be quicker. I think is that it? Yes.

>> I'll turn the mic on, okay, so I'll talk a little bit about why PEP and what we're doing with PEP. When I was in -- in 1990 or so I was in Alaska at a hospital. And we started doing high risk screening. And I used the JCIH recommendations. And then in 1994, fortunately they came out with the next one that recommended universal screening and I moved to Arizona and started the universal screening. So I've been following the JCIH a very long time. Maybe not the 70s because I have a little kid then. But we are using JCIH for the basis of educating and improving EHDI. Part of the reason for that is to provide that common messaging. And to not spend time re-inventing things.

JCIH has been methodical about reviewing the literature and building consensus with the organizations that are a part of it. And that way we can focus in on how we convey that message and get that message out, rather than having that argument that you all had over and over again about which words to use. We just incorporated the words that JCIH agreed on. We know in 10 years it will change and we'll have to have different words but for now we are using that. So we are trying wherever we can to collaboratively develop materials, promote that 1-3-6 plus, the plus being the parent-to-parent support. And educating providers what their role is, the timing what the expectation for other EHDI providers and not just themselves. But other professional roles as well

And recently we started working on PEP materials to empower parents with the knowledge of roles and expectations and really to enhance the opportunities to have stakeholder that collaboration and to have materials that can be used by anyone across the nation not just one program.

So one of the goals is really to remain true to the wording of JCIH. And to target materials to specific audiences. Because the -- because JCIH document is 44 pages long, other than EHDI coordinator, anyone read the whole thing?

Not everybody. And you guys are all in EHDI. So it is our gold standard document. So the fact that a lot of you haven't read it is because it's probably too big and too dense for you. So we are trying to target it to specific audiences so we can pull out of the JCIH document that part that's most significant to audiologists and create a checklist for an audiologist that breaks it down into a manageable amount of information.

Because there's such valuable and, you know, really, really well thought out material within that, we want to be able to break that down into usable pieces. We want to promote that consistency and messaging. And one thing that randy is up here, she'll talk about the EHDI-PALS and the newborn hearing curriculum. These are the materials that use some of the same ideas and based on the JCIH and try to be consistent with gases

So we embedded some of the PEP materials in there as well. So we want to make sure we have the consistent messaging so doctors and audiologists are hearing the same thing, and hopefully downhill that parents are hearing the same thing because we hear over and over from parents that's a real source of frustration is hearing different things from different expert providers.

So we also really believe in the steal shamelessly and promote -- share shamelessly and steal shamelessly. So we want to make sure anything we create can be used by other states as well. So we can assist EHDI programs specifically in meeting their federal grant requirements not just this year but the next grant upcoming. We assume there'll be information in there that is going to be useful to help your next EHDI requirements. We know the grants have not increased in funding. And the demands have gone up. So --

So we have providers checklist and you can go to the QR code and look at that. And the provider checklist, this is primarily for the first few are for audiologists. And they are just checklists of best practices. And so if you take a look at those checklists you'll see you can use them in several different ways. You can use them at your EHDI program so look at what is coming into your program and does it meet the requirements and is this what we really expect to see? You'll notice on there it has frequency-specific ABR, not click ABR. And things like that that you'll see are expectations of what a -- what we expect out of -- or what JCIH expects. Same thing with amplification. One thing that's new in there is the audiology oversight the recommendations for audiology oversight. And we used that within programs to say, wait a minute, you don't have an audiologist looking at any of these things. At the hospital level. At the state level. At whatever level there is

really an expectation that you will have this audiology specialist taking a look at the program and providing insight.

It goes into risk factors. Risk factors have a role in the newborn screening but they also have a big role in late onset and progressive hearing losses which is really falls within the purview of the audiologists, the family and the home provider. So all of those together have to work to getting those risk factor information. And early childhood screening. As we are looking how to improve screening in the 0-3 beyond newborn phase we need to start looking at early childhood screening and what you really need to be able to do that well.

So provider engagement. So one of our requirements for our last NOFO was provider engagement. So they really want to make sure it's in JCIH as well that we want to make sure that our providers are educated and knowledgeable about what to do. As you know, a pediatrician may in the see another child who is Deaf and Hard of Hearing for many years in their practice . And so we are always looking at what can we that's more just in time? What can we do that's a place where physicians can find information they need then? Some of the things that Randy will talk about as far as the EHDI-PALS is focused on that.

And we want to make sure they have that role in making referrals, making timely referrals and making sure that the family ends up where they are supposed to be at the time they are supposed to be.

>> I'm the duck. So with that, you have a QR code again. If you didn't scan the last one this is the same landing page as the previous one. Both of them are both QR codes like I said are the same but it will take you to the parent and provider materials. I do want to point out we do know that the parent materials have the word draft across them. We are still going through some more quality improvement process. And fine tuning them. Bewe did to make what we have out so far available. And our current pages are listed here. The newborn hearing screening. Early Intervention. Audiology eevaluation. And medical home. These are based on the recommendations. What providers should be offering families.

And the protocols and timelines that families should expect because we know that parents get mixed messages. So we want to empower those parents to understand the timeline and what should be happening and when. On the parent materials there are QR codes, I get poked fun because I'm the QR code queen. But I do find they are the easiest way for a parent to access the information and get to that resource. They are broken down into simple blocks. They have a nice, light kind of air to them.

But they are bulleted points. Easy for families to digest and go forward with the materials. The QR codes then reflect back on more information on that specific topic

So how did we get here? It was not like oh let's sit down and figure this out. Lilah and I had discussions with the FL-3 center. What do we see as far as information that we should provide for families? What is our already out there? What should we consider for those links for QR codes and such

And then they were created, language was softened. But still direct. And then we took a quality improvement work group to look at that, provide us feedback on the design, provide us feedback on the language. Helping them understand a little bit of the background of the JCIH recommendations. Because they are -- they weren't parent leaders. Which was perfect. Because they are the ones that we would be providing the information for. So we want to make sure they can understand it. So let's see, we plan on and hope this would provide information and education for the family-based organizations. So that they could take this and pay it forward, roll it forward, right? Let's keep this thing moving. And that QR code and like I said here at the bottom, bullet point on the Illinois sound beginnings website is where you can a access those materials. Next slide.

Okay. So again, just engaging and empowering and letting parents know they have a voice. I know at my beginning, I went with the flow of the providers. And their recommendations. So knowing that I could speak up and maybe not challenge but question the time frame that the provider was suggesting or maybe the amplification direction they were recommending.

I just feel that well inform l families are better off down the road and they are able to access the tools they need.

So again, also making families know and be aware of that 1-3-6 process. And reinforcing terminology. This is a lot of new information when parents come in. they don't understand these terms. JCIH. And I know as a parent when I sat down and read JCIH materials I was like okay I got to set this down and walk away.

So that was the purpose for the parent pieces.

>> So JCIH materials by the way, were realtime written for parents and the parent materials is actually taking us longer than the other materials and by the way this was Kerry our QR expert and a mom. So those materials getting them into a language that's more accessible to parents and at the same time staying true to JCIH has been an interesting road, let's put it that way. I think this one is Randy

>> Yes, the newborn screening training curriculum if you are not familiar with it. I think many people are by now. But it came out in 2012. The reason that we decided to develop this wonderful tool is to take the messages forward to screeners. And the messages were from the -- now I'm forgetting what the JCIH 2012, right? No, what was -- 2009, right? 7 and 19, I can't believe it was that many years. But 2007 position statement. And thereby we could train screeners to use best practices as stated in the position statement and also use equipment as it's supposed to be used and that mearnlg between using best practices and knowing how to use equipment which is also part of the curriculum, there's the hands on piece, would produce really successful outcomes

And then taking the messages to families through scripts. And empowering screeners to have knowledge and education which would then give them the confidence to do a really good job. That's where we started with the curriculum and the JCIH. And it's gone pretty well I think. The majority of the outsourcing companies are using it.

A lot of hospitals are requiring it. So a lot of people are getting access to it. We had a lot of participants and we are excited about that. And when the parent materials come out, we'll be adding them to our resources. And integrating them. We have a new curriculum that's coming out and outpatient screening we are calling it the newborn training screening curriculum for community partners and it will be specifically geared towards mid wives and doctors and community health clinics and anybody not screening a bo in a hospital

So that's coming at some point, we are working on it. But these tools will be fabulous, especially to provide to families for parent education. Yesterday I found out that ASL scripts are available. So they'll be posted soon as well. No, please, jump in.

So EHDI-PALS is a national directory of pediatric audiologists. It's geared for families who are trying to find quality audiologists in their communities. It started out that way. And it was developed, again, with the intent that we are going to ensure all audiologists who are enrolled in the directory are following the practices in the 2007 position statement. And so when audiologists are filling out the facility survey, to answer a series of questions that's an algorithm they have to go there. And it's in multiple ways identifying that audiologist has the equipment and the skills to provide services. And to be enrolled in EHDI-PALS. So audiologists that aren't able to demonstrate that through the facility survey won't be displayed in EHDI-PALS. Again, this entire survey was developed years ago. With an advisory committee of experts throughout the country. And all different multidisciplinary roles in EHDI. And it's

brilliant. And it's not I think an audiologist favorite things to fill out but we are getting more and more participation, which is great.

I only have a few more minute, right? I could go on and on, that's my problem because I'm so passionate about this. So through this, through EHDI-PALS, families and providers can search for health care providers can search for audiologists. And let me see what else do I want to say? And get all the information detailed information about an audiology clinic. Again, we are trying to ensure that families don't get lost. And that there's a cannelless hand off between the 1 and the 3ment and that's the original intent of EHDI-PALS and we really, really follow that. As expanded we are using now we have a family -- we have family resources and we just released professional resources. I'll be presenting at 4:15 on those professional resources in room DEC I think 205 about those professional resources but in the professional resource are scattered those six PEP checklists. At the end of the facility survey we have used the hearing evaluation checklist

at the very end. And an audiologist before they can sign off on their survey have to check off every single box to say, I acknowledge these practices. They don't -- we can't prove they are using them but to see them and over time, hopefully they'll adapt them if they are not already

So the consistent message of messaging is what's critical, multiple overlapping strategies that we were using in these programs to get these messages across. Thank you.

>> And that is Randy Winston she works for AMSHA many and she said we developed this for whatever reason but the reason is she worked for Arizona and we couldn't clone her fast enough to get her to all the places she needed to be so we created a standard training

>> We have postcards with QR codes, thank you, Kerry, I have some of these if you would like to grab them. I have them up here at the end. And we have stickers. These are wonderful. Again, they can go on equipment. If a family doesn't pass the screening at some level, it can be on the screening equipment. And they can just put their phone and camera right up to it. And plug in to EHDI-PALS.

>> We are hoping at some point in time we can talk Randy to put QR codes on the newborn hearing screening training curriculum scripts because in my state we laminated them and attached them to equipment. So we are really looking forward to that. So what was your question? Absolutely. Absolutely. Those QR codes. And that's a Kerry thing. As you can see, Kerry is more technologically advanced that's than the rest of the crew up here. She does our best and we try. We have some handouts up here. I'll get them while Ginger talks here and I'll get them to hand out and you can get the QR codes there as well

>> If you are old enough to know who Paul Harvey is I have to tell you this story. She teases us about the fact of the QR codes. She came in and said we need to put QR codes on this. And I said I hate QR codes and we tried them at EHDI at a conference a long time ago. And I --

>> It was suggested then

>> So she was ahead of her time then. And I was like I don't like them. And what we learned though is things that are a good idea Kerry does anyway. And then I eventually -- well, she proved -- she -- she put it on and says let's just test it. She's steeped in the quality improvement. She's a long time fan of quality improvement. We'll try it

And I said all right let's try it. And it proves I should have listened to her in the first place. So listen to your parent partners. Listen to the people outside. Up at that table you have Hands & Voices guides by your side and you have audiologists and AMCHM and Arizona and Illinois, I mean, this crew represents a lot of different organization. My challenge to each and every one of you, get out of your silo, and partner with other people. And come up with some projects that we can share seamlessly and steal shamelessly, but have your eyes and ears open to other folks and even if you think it's not the best idea you get proven wrong over and over again but it's actually a good thing. So we thank her for doing these QR codes

What can you do by next Tuesday that meets your grant initiatives? It's stakeholder engagement and education is big. You can take if you want the artwork for the stickers and you want the artwork for the postcards if you want to do a PDSA on stickers we'll have them tomorrow at the EHDI coordinator meeting. We ask that you give us your email address so we can do a follow up quick survey with you to see how you used them and if they were helpful to you. If you want the handouts attached to today's presentation, that have these QR codes on them, let us know, we will share those with you

If you want the web links we will share those with you. That's what you can do by next Tuesday is take what we are created and send it in an email blast

What Lillah created and we hope you'll take there's sample emails written in here with activities that you can go home and implement right away. So it's just a sample email, guys, put your own spin on it, your own flavor, season it up the way you need to for your community. But it's in there so you can send an email blast to audiologists, physicians, parent organizations to share the information. We got the graphics we got the QR codes, those are already there

Leverage the opportunities that you already have. We use Mail Chimp, again you know who create that had account? But we get analytics out of that out of how many and that's a great thing to put into our grants. So I'll stop there so we can open it up to questions or comments

>> We have a couple questions out here. Thank you very much. This is our contact information as well. There was a question way in the back. And now she's taking a picture instead of asking a question. Somebody bring that mic

>> I'll do it.

>> Kerry does everything.

>> So I'm so excited to see the referral to a pediatric audiologist. I'm a mom of a Hard of Hearing daughter. And my undergrad is in public policy and masters in public health. But but it wasn't until the fourth audiology appointment -- and I worked at a children's hospital -- thaw we found someone that could test the hearing. And had the right equipment and could dispense the hearing aids. So we lost months. And so I'm so excited to see this. And so my question for you is, my -- sorry, my pediatrician sent me to the adult provider. What are you doing with AAP to kind of circle make sure this information gets out? Even a simple video. And maybe this exists already, but I feel like there needs to be something that describes what is the difference between a pediatric audiologist and a dispensers and a audiologist. A we are struggling with this in California because the State of California origin nayly ended up on our program as a hearing dispincer. And a mom called

through 100 providers and none could serve children. So we got a specific list created if you are our famils that were pediatric audiologists

>> Other the years as the coordinator in Arizona I have written to insurance companies says none of your providers do what we need to be done. So we'll add that to our list of what needs to be done. That's Phoenix's children hospital calling me

So we'll add that our list of things that are high priority. And we have our chapter champion here so we'll add that to his list of the things we needs to accomplish very soon as educating pediatricians about what the appropriate pediatric audiology providers. I know a lot of EHDI coordinators struggle with that and some are doing things with their follow up to make sure they are getting that information to parents

Some places are helping with their guide by your side programs. But it is something because they are a unique group. I think if we can encourage audiologists to enroll in EHDI-PALS that's a one-stop shop nationally that was the same standards across the nation. And it has standards based on that JCIH. So based on a consensus statement across many different organizations

[off microphone]

>> The comment was getting on the conference panel for at one of those meetings just for communication access I wanted to add that. What you can do by next Tuesday though is put the EHDI-PALS.org website on your letters that go out from your health department. That's a small thing but it's a step in the right direction

>> Or the QR code for it.

>> But as you look in EHDI-PALS and you look at the like depth of information, it really helps a family feel empowered in knowing what is -- what like insurance they take. What accessibility accommodations do they have? What languages they have interpreters for? It's on and on. So they can identify that audiologist that meets their needs.

>> I think all of us are all about empowering parents so parents know what to look for. Because you don't know what questions to ask when you are first heading out what you don't know what to expect. So how can we expect parents to do what we want them to do if we haven't told them what we want them to do? And given them the information they need to have that make sense to them

Any other questions?

All right. My facilitator back here kept waving signs at us so I think I'm supposed to tell people to fill out the form online. So go ahead and fill out in the app your evaluation form. And come up and pick up the different pieces that we printed I printed them and I'm not carrying them so come get them

[applause]