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NCHAM – EHDI PALS
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>> We will be starting this webinar in about two minutes. We're getting our presenters settled in and participants are signing in as we wait here for a few more minutes. You can adjust the volume to your liking using your headset or speaker volume setting. You'll be communicating with a text field that will be displayed in the presentation when our presenters will be take your questions. So I think we're about set to go. We'll wait about two more minutes and we'll get started.

>> I am going to initiate the recording of this webinar so it can be put on the NCHAM website. I'll turn it over to today's host, Erica Blanchard. Sit tight, Erica and I'll give you the heads up in just a second. Okay. We're ready to start.

>> Good morning, everybody. We would like to welcome everyone to today's webinar. Successful strategies for promoting EHDI Pals with healthcare providers and parents. Presented by Arizona department of health services, office newborn screening, Fran Altmaier, Sondi Aponte and Gidget Carle. Hopefully I didn't butcher your names too poorly. Today's webinar is brought to you by the national center for hearing assessment at Utah state University which serves as the national resources center on early hearing detection and intervention.

This webinar is part of a series that NCHAM is sponsoring to highlight key topics of those interest to those involved in the EHDI programs on a national state, and local level. Joining with the move the needle initiative, the national center for hearing assessment and management. It is committed to moving the needle through continued efforts to assist with implementation and improvement of comprehensive and effective early hearing detection and intervention systems. My name is Erica Blanchard and I'm a pediatric oncologist. I'm part of a -- I'll be hosting this morning's webinar on a topic important to my home state as we're looking for ways to increase the use of the EHDI health pediatric registry. We will have a Q&A period at the end of the presentation. There will be a chat box for you to type in your questions for the presenters. Today's webinar will be record and posted to the NCHAM website under the move the needle heading. There is a link for closed captioning. It is on the left-hand side of your screen. If you scroll down, you'll find the link. If you need closed captioning as well. I'll now turn things over to Fran and her team to share with us how Arizona has promoted EHDI Pal to the healthcare providers and parents in their state.

>> Good morning. Good morning, everyone. My name is Gidget Carle. Before we get started with the presentation, we would like to introduce ourselves and tell you about the different areas of expertise we bring to the program. I have a BSN I am the well baby follow-up team lead. I oversee the activities performed by the hearing follow-up team specialist. I'm monitored the progress being made based on the 1-3 goals. I have more than 20 years of experience including five years as a clinical manager that provides screening, testing and education to the public. Now, I'll turn it over to Fran.

>> Good morning, I'm Fran Altmaier and I am a social worker and I currently am a high risk coordinator here at the department of health and I follow up on all of the NICU babies and provide the follow-up services they need. The new grant -- the project specialist working on the CQI projects.

>> Then we have Sondi Aponte. We're trying to remote her in, as well. I'm wondering if Sondi is on. All right. Sondi, are you there?

>> I am. Can you hear me?

>> Yes. Hi, everyone. Sorry about that. I'm working remotely and at a conference today. Thank you all for attending. I'm going to take a secondary role and will only jump in a few slides to tell you a little bit about Arizona. I've got about 15 years in education quality improvement and technical training and I've worked most recently for the last seven and a half years with Arizona EHDI and other newborn screening services. Thanks for coming.

>> This year at the EHDI conference in Florida, we presented a poster on successful strategies of promoting EHDI Pals with the healthcare providers and parents. Our poster illustrated the steps that we took to get the message about -- to get the message out about EHDI Pals and the new website. We will go more in-depth to the following in the following screens. Erica Blanchard contacted us and asked if we would do the presentation on promoting EHDI Pals with the webinar format. We're very excited to be given the opportunity to do this presentation and to share this with a broader audience as well as people who were unable to attend the conference.

>> SonDi, are you there?

(No audio).

>> Okay. So just a little history about EHDI Pals. It was created by the CDC as a national web-based directory. It was a place that parents and professionals could go to find a qualified pediatric audiologist. The benefits are you're able to search any state which, as you saw the demographics of our state, is helpful because we have all of the states that border on us and we have families that live in those communities. It is really hard to get to Phoenix to see an audiologist. This is a really nice way for families and primary care providers to be able to locate an audiologist near where a family might be. And then also allows you to find an audiologist or a provider that can complete the specific tests that your baby needs. Not every -- as we all know, not every provider is able to complete the same type of test. Some babies only need a screening. Some need a diagnosis. And this is -- this allows you to easily find the provider that you need.

Okay so we saw an opportunity with EHDI Pals coming out and move the needle. It speaks to what we try to do. We were recognizing EHDI Pals could be a better way to find a qualified audiologist. There was no upkeep on our end. The paperless we had been using, it is maintained by the CDC and the standards they're requiring providers to have to be signed up on EHDI Pals. It allowed us to find providers in bordering states. And it was easy for both parents and professionals to use.

For many years, the office of newborn screening had a self-created resource list. We shared that with both parents and providers. It was a tool that helped them be able to locate outpatient screening and diagnostic sites. Some of the concerns with the paper list was it was not always accurate and it became cumbersome to keep up with.

>> The other thing, too, about the paperless that we had was we had to send out a different one, depending on what kind of test the child needed. We had a separate list for screenings where you could go for an outpatient screening. We had a separate list for where you needed to go for diagnostic testing. It was a judgment call as to which letter to send when and a child may or may not be in that right stage of the follow-up process.

>> So with the paperless, there were some pros and cons. And the pros on that was that the providers felt it was handy that they could hand a resource letters out to the

parents. It was available on our ADHS website. It was easy to read. We had it in English and Spanish. The screeners could give out to the family at the time that they failed the hearing screening. It was easy to send to the family -- with the family's letters. Some of the cons to that was trying to constantly keep it current. It became outdated quickly. Sometimes it was confusing on which list to give out since we had two of them. The cost of maintaining it became real expensive. And the time it took to constantly continue to update it. So there was no standards for the list of who was on it, who was not. And it could be subjected to whatever was going on.

So some of the pros and cons to EHDI Pals website being new was it was standardized. We had -- an objective to it. The providers were responsible for adding and removing themselves. It was a resource for the parents and professionals. It was a national resource and it could be -- you could find a provider in any state. Some of the cons to it was it required Internet access and families needing to figure out how to use it and time-consuming just for states to build their own network provider. And becoming providers, being responsible for adding and removing themselves.

So this is where we thought, where do we begin? How do we get -- make the switch from our paper resource list over to EHDI Pals? So what we did is we started by contacting our Arizona office of special licensing located here at the department of health. We had a meeting with them and told them what we were trying to do. Through that relationship, we were able to get a listing of all of the licensed audiologists in the state of Arizona. From there, we created a letter and the next few slides will give examples of what we sent out. We created and sent a letter to all of the audiologists asking them or informing them about EHDI Pals and how to register. A few weeks after that, we sent a follow-up e-mail blast for those that we had e-mail information.

We were able to e-mail them as a follow-up reminder to go visit the EHDI Pals and sign up if that was appropriate. We posted information on it on the department of health services website. We promoted it using either social media, the department of health has facebook, has twitter, has Instagram. We were able to use our other social medias to broadcast out about EHDI Pals. And then we compared it to our old paper list. Who was on our paper list and was not yet signed up for EHDI Pals. We brought in the help of our state EHDI coordinator who made contact with those audiologists that we knew were pediatric audiologists and hadn't signed up for EHDI Pals and she provided one-on-one assistance with them to make sure that they started and completed the enrollment process on the EHDI Pals website.

So you can see here this is a copy of the letter that we sent to all of the audiologists. We can make all of our handouts or all of our do you means available after the presentation if anyone wants to be able to read specifically what our letter said.

This is just a screen shot of the e-mail blast that we sent out to all of our audiologists, as well. It included information about EHDI Pals. It also included a link to our latest edition of the EHDI newsletter at the time which is the one that featured all of the information about EHDI Pals.

This next one, you can see that we created a flier that was easy to read. It was very simple for a family and a professional to understand. We were able to have it translated into Spanish so we have it available when we send it out. It is two-sided, English and Spanish. So it is the family's preference. Spanish is the second most common language in Arizona so that's why we've only targeted it in Spanish at this time.

So what we do with this letter is we currently send it to parents with the follow-up letter. We FAX it to all of the healthcare providers. When we send a FAX back form asking for the next steps for where the child needs to be referred and then we also have it available at all of our conferences. Any time we're out networking, doing outreach, we share the EHDI Pals flier because it has so much good information in it and it's accessible for parents and professionals.

So on the last slide, Fran touched base on all of these areas of how we spread the word. Sending out a letter to the providers via FAX back or mailing the letters to the parents, as well. And as she said before, using all of the -- adding it to the EHDI website along with all of the social media. So we can just kind of move on to the next one there.

Okay. So our EHDI newsletter, we dedicated our July 2013 edition of our EHDI newsletter to EHDI Pals. It featured an article from our chapter champion. It had tutorials on how to use it. There were screen shots showing examples of what somebody will see when they visit the EHDI Pals website. It highlighted the parent resources that are available on the website. And then there was an article included from the high-risk coordinator update with information on using EHDI Pals. The newsletter -- it promoted the EHDI Pals logo development we had it throughout the newsletter. We highlighted about the parent resources, the dissemination strategy.

When we send out our newsletter, we disseminate it broadly. It went to all of the Arizona academy of pediatrics list serves so every pediatrician received a copy of the newsletter with this information. We sent it out to our early intervention providers. We shared it our home visiting programs with midwives. We made sure audiologists had it. They're all on our constant contact list to receive our newsletter. So it was really able to reach a broad audience.

So this next slide just shows this is the letter from our chapter champion. Are you EHDI ready and do you know your EHDI Pals. His article talked all about being able to use and the importance for a pediatrician and the impact it would have for them. This one had some of the screen shots. And this one here actually was where we had a tutorial on how to go and -- sorry, that was -- where we did the tutorials and showed them how to fill out the information and you could find a provider in the area where you lived or close to neighboring states. And also added -- also, there is a link in there so for the parents, if they wanted to know about more information, what kind of questions to ask at various stages, how to communicate with their children and with early intervention and to maybe help meet other parents who had the same type of support or needed support with this process.

This last slide, from the newsletter is the article from the high-risk coordinator just talking about using EHDI Pals to find a qualified audiologist.

So in summary, this is sort of the results of our efforts in promoting the EHDI Pals. We sent letters to 301 licensed audiologists in Arizona. Our state EHDI coordinator made six targeted contacts to known pediatric audiologists who had not signed up for the EHDI Pals. Of those six, all six did sign up for EHDI Pals. We currently have 31 audiology facilities in Arizona that are registered with the EHDI Pals. We continue to disseminate the flier at all conferences, at the exhibit tables, any outreach efforts we have, anywhere we go, we bring the flier that we had shown earlier, the one that's in English and Spanish. We take that with us. So just some of those

statistics, when we originally did the poster, we had the -- from November 1, '12 to March 10 of 2014, there had been 3,190 unique visitors to the EHDI Pals site. Which resulted in 63,000 page views on the EHDI Pals website. Since then, since it started November 1st of '12 up and through the other day, you can see that there were 4,819 unique visitors which resulted in 92,000 page views on the EHDI Pals website. So just in the past six months, EHDI Pals has had almost 30,000 page views. So it is hard to know who's visiting as far as repeat versus new, you can see a lot of people are going to the EHDI Pals website to find what they need.

And that's where we can now open it up for questions.

>> The box that says Q&A, feel free to type your questions in there for the presenters.

>> Has there been any progress to your knowledge about making EHDI Pals available -- make that bigger. In Spanish. And that I don't know. That's something that is a really good question. Because hopefully it will be made available in multiple languages. But I think on the website -- does it have -- English and Spanish?

>> I think it does.

>> How many audiologists from our state did you say signed up and how many pediatric audiologists are there in Arizona total?

>> 31 pediatric audiologists are currently signed up for EHDI Pals. And that is -- that is the total number of pediatric audiologists that we -- that are currently seeing our children. As new audiologists move into the state and join existing agencies, we make sure that they know about EHDI Pals and that they're signed up for it.

>> That is constantly a dynamic changing. Rather changing from one facility or moving out of state or as Fran said, coming into the state.

>> The next question, how is the success of EHDI Pals nationally? The statistics that we gave at the end actually has nationally. That's not just for Arizona. That is national. The back end of the EHDI Pals website has some of those analytics but it does not break it down by state. It does just national information on it.

>> Maintain the EHDI Pals website long term?

>> That's up to the CDC. I haven't heard if that is going to change but that's where the EHDI Pals website currently resides.

>> Anyone got feedback on how parents use this site? Do they tend to go to the closest center geographically.

>> Those are great questions. We have the same questions. We're still trying to figure out how we can identify how well parents are using it. How easy it is to understand. We haven't gotten any feedback from parents. On the ease of using EHDI Pals. That's probably something really interesting to look into, to find out are they finding it as easy to use or easier than having received a paper list.

>> Does it list the practices that are fluent in Spanish?

>> Yes, it does. Because it lets them know which language is available in each practice, whether it's Spanish or any other different language.

>> The next question was when contacting the Arizona office of special licensing, were they able to let you know which of the audiologists were pediatric providers or was there a specific process you completed to determine which of all of the state audiologists services provided pediatrics 0-36 months. The list we received of the 300 audiologists was all audiologist whether they served babies through adult, we didn't differentiate. We sent everybody the same information. And some of that's good because they

needed to know about it. Because they may get an inappropriate referral and this will give them a way to find an appropriate audiologist to refer a child, too. And then we know -- or we knew who all of our pediatric audiologists were from the consulting audiologist we work with, from our state EHDI coordinator, we were able to identify who our pediatric audiologists were and that's how we knew who to target after we did the mass mailings and mass e-mail to find out who was enrolled in it.

>> Question, do you have any early programs who want to find out where audiologists are but not with a specific child in mind. How do you use EHDI Pals when it is a general list of audiologists rather than serve a specific child? I think we use the list in a way that we're not giving a list of providers to a parent because we need a parent to make their own decision and that's where this becomes a really good tool for them to go on there and hopefully an early interventionist or early childhood program could work with a family. Let's work together and see who's near you. Who has the ability to do the testing you need and what a parent -- and let a parent make their own choice rather than recommending maybe a personal preference for a provider that we have. Take some of the bias out of it.

>> This is also beneficial to families that may not have Internet access.

>> And then their early childhood provider, somebody can help search and bring them a list of providers that they found in their zip code. They could spend a session reviewing that and seeing where they could possibly do that.

>> Did any of you audiologists have issues signing up for EHDI Pals and filling out the required survey? We use the resource of our state EHDI coordinator to reach out to the audiologists to make sure. It does have a field in EHDI Pals where there is a pending one where they haven't finished the enrollment process. Our state EHDI coordinator is able to walk them through that process.

>> Have you considered additional strategies to increase the registration from providers? As far as that is our state EHDI coordinator is the one who has done -- has reached out to providers to make sure that they're enrolled. Typically, it is a small community of audiologists that our EHDI coordinator knows if there is a new one in the state to reach out to and make sure that they go in the direction that they need for signing up.

>> At present, how many state EHDI Pals -- how many states has EHDI Pals been established in? That I don't know the answer to because it is a national resource. We just know of what's available on our state and then the efforts we've gone through to promote using it in our state. But that would be more of a question to direct toward the CDC to see where they're at with that and how many states have enrolled. Actually, I think you can see on the website if you have access to the back end of the website, you can see how many states have signed up for that.

>> Are you concerned that any of the audiology sites that are on EHDI Pals should not be listed? That's an interesting question. It takes our bias out of it if an audiologist meets the criteria to sign up for it, we have no control over that. And you know, I think that asking that question is sort of a slippery slope on how to answer it. But it does take all of the bias out of it. We have no say in it.

>> That's one of the great things of having the CDC do it, it makes it more in their hands so it is more subjective and objective with it being that way. They're in control of who's on and who's off.

>> The next question is do we have challenges with border babies but EHDl Pals has helped us address? And we're very hopeful that EHDl Pals does help a family in a bordering state find an audiologist. It does necessarily address that we have a large population of families that come back and forth through the Mexico border. So out of the country, it is hard to say. Going state to state between Arizona and our neighboring states, we're really hopeful that it is an easy way for a family to provide -- find a provider that may be closer to home for them rather than driving all the way to Phoenix. Because Phoenix is a really far distance. I mean if you saw on the original -- let's see, let's go back to that slide. With the map of our state. Phoenix is sort of in the middle but down maybe 2/3 of the way down from the top is where Phoenix is. So if you look at the very northeast corner of our state, there's a lot of people that live that far away from Phoenix. And it can be a six-hour drive to find an audiologist. So we are hoping that families have been able to find providers in some of our neighboring states. Any other questions? And again, we said if you're interested in receiving information or copies of the forms that we created, letters, you can e-mail us and we would be happy to provide copies of the information that we created to share with you.

>> Contact information is listed on the left-hand side of your screen. Thank you all so much for that presentation. I know that I found it incredibly valuable and I hope everybody else enjoyed the presentation as well.

>> Thank you.

>> Thank you.

>> If there are no more questions, we'll let all of you get back to your very busy days. Thank you all and have a wonderful afternoon.