>> My name is Brenda Humperdinck and we are going to start a little bit early. I am the room a moderator, so I will be in the back of the room, so you have any questions or concerns, you can come and see me. I just want to remind you that at the end of the session, if you could please go on to the event app and fill out the surveys after each session, and if you need help getting that C event event app downloaded, you can come and see me. Now I am just going to welcome you to the session this afternoon: The EHDI expansion to include screening children up to three years of age. I'm going to turn it over to your presenter who is William Eisenman.

>> Thank you. Good afternoon, everybody. I am going to step out in front here. How is everybody? Good? Avco feel free to come forward if you are comfortable. We don't have a lot of people here. How many of you are EHDI coordinators or EHDI staff within your states? Wonderful. It is wonderful to see you and me you all. I am a well I sermon and I'm at [ INDISCERNIBLE ] at the EHDI and TRC for about 20 years since 2001, to 22 years I have been directing an initiative called the Echo initiative, which is the early childhood hearing outreach initiative that has focused on birth through three screening. Long before we head to the time period that we are in now, with the reauthorization of EHDI of 2017, where now the pot is really stirring about how that expansion is going to start to manifest in practice. So we are going to talk about several different things today, and I want to start off with a thank you to our interpreters, and our captioners who are working with us throughout this conference. Sometimes these folks aren't acknowledged fully, and I really want to make sure that we all note with an applause for their help. So thank you.

[ APPLAUSE ]

Thank you. We don't want you to ever think that we look through you as if you are not another human being who is part of all of this, and I also want to thank one of my colleagues, Jeff Hoffman, who many of you know, who used to be the EHDI coordinator for Nebraska, and then worked alongside us at N Jam for a while. We are going to be talking about a project that he helped us with today, so I just want to make sure that he is given proper recognition, as well as Terry Faust, who is here, who has been our pediatric audiologist consultant for many years, and if we have any technical related questions today, Terry is going to help address those. So I mentioned the reauthorization of the EHDI act of 2017, because in there, it requires that we start identifying children beyond the newborn. Up to three years of age, and the reason why that is so significant, just so we are all on the same page, is that it really does represent the potential of doubling the effects of EHDI, from identifying about three children in 1000 at birth, up to six per 1000 or even more by the time children enter school. And if so, that is a pretty significant change. Everything we have always said about why the EHDI program or the EHDI system is so important is reinforced again as the same justification for expansion. And so that is humbling, and I know it is overwhelming when you are already operating with a very thin budget, very stringent time demands and other resource demands on you. So we are really thinking about a process. The nofo, as you know, does require a plan for expansion, and that plan is currently due in about six weeks, at the end of April. And so, we will talk a little bit about that plan and some of the guidance that HERSA has given us. I want to also acknowledge Shelby Grace who is here from hersa -- she is our project officer, and I will be including some of the information that she has shared with me about helpful considerations as you continue to polish up your plans, so we are going to talk about our environmental scan, study that we did this last year covering a lot of the different elements that go in to birth through three screening. We are gonna talk about the resources we currently have at NCHAM and may be helpful to you, and then we will talk about those considerations. I can't acknowledge what you all deserve to be acknowledged for as far as how far you have bent over backwards to do the work that you do. All of the ways that you twist yourselves up to see things from different perspectives, and all that is expected to do that, and how many times you are stretched and stretched, stretched some more. It is not a joke. I mean, it really is a lot that is expected of you, and this latest expectation is one more eye roller, but like EHDI was from the very beginning, we are talking about taking steps in an expanded direction. It's not going to happen overnight, it's not going to happen while you are already doing exactly what you are doing right now, it is going to take time and increments, and I hope that some of the ideas that we have, based on some of the experience that we've had with birth through three screening over the last 20 years can give you some ideas about what those steps could be that would be meaningful steps toward more children eventually maybe almost all children who can be identified subsequent to the newborn period. So we did an environmental scan which was an opportunity for us because HERSA said let's pull it all together. Keep it working in the area of birth through three screening for 20 some years, but let's pull all of that information together, so that as various experts from multidisciplinary teams come together with the question about how they can do this, that there are some resources where they can all go to at least start to decide how they want to move forward. So I want too just acquaint you with the environmental scan report you will find on our website so you will know what you can find there. We don't have time to go into the detail the content of it, but I want you to at least know what you will find there. We talked about evidence-based and evidence informed approaches to hearing screening, including schedules, protocols and guidelines and recommendations. Locations where screening can occur including policies and practices of potential partners around birth through three screening. We talk about collaboration and referral mechanisms, including data sharing agreements that various states have had. You know, some of you here have been involved with birth through three screening, whether in collaboration with us over the years, so some of this comes directly from you but is valuable for others to learn as well, and then the potential roles of EHDI programs, including strategies, stakeholders, educational methods and ways to progress. So this is our table of contents. It is a pretty thick document. It has the recommended screening approaches, it has screening approaches that are not recommended for birth through three populations per periodicity schedules, protocols and guidelines, a section on settings, what settings are most conducive or already available for screening. There's a part in here about part C. Those were our primary focus so we can talk a lot about that if any of you are going to target that particular group to collaborate with as a part of your first steps in that direction or next steps. Collaboration mechanisms and referral mechanisms around data sharing and the role of audiologists and other community-based partners. And then we talk about, and I'm going to get a little bit into this in a moment -- about some of the ways that you can move the needle, whether it is looking at doing outreach throughout your state, just making people aware of the importance of ongoing screening throughout early childhood. That is a big undertaking all by itsel. Educating the public and the community, all the way to helping build actual screening programs, so there is a whole continuum of ways that we can start to grow this birth to three piece. So we will talk about that. So check out the environmental scan on our website as a resource, and hopefully that will be helpful. Now, when we talk about the birth to three screening endeavor, often our minds just go right out the door of the hospital, out into the community, and we start thinking about all of the ways that we can find a children to screen them, subsequent to the newborn period, but before we go out the door and leave the newborn period behind, let's pause and think about two other things that may be can occur as a part of newborn screening. And the first is to think about CMV testing. That if we wanted too seriously identify children in that birth through three program, we need to remind ourselves that one out of 200 children are born infected with CMV. And one out of five develop health consequences, the most common of which is a hearing loss. Often developed after the newborn period.

So they can't be identified at birth but they can be later. So identifying those children as some states are doing, Minnesota is embarking on a serious commitment to this, right ? That is a gigantic step forward in building the capacity to identify children subsequent to the newborn period.

The other opportunity is a big deal, but it is genetic testing. For all of those conditions. I mean, we know that 50 to 60 percent of children with hearing loss have a genetic cause, and many of those don't manifest until after the newborn period.

'S what we really wanted to find children and that birth to three period, that would be the way to do it. It is a loaded deal, because we wouldn't only find children with hearing loss, we would find a lot of other things, too. Not the least of which is surprises about who the fathers are pure

[ CLAP ]

It is a big deal, but it is a way that we can make dramatic improvements in that. So as you think about your plans moving forward, don't skip over this too fast. If you have a pioneering spirit about you, I want to remind you that the EHDI system that we know and love and work inside of today, was because of big, radical thinking. It was pioneering thinking, and some of those people who were a part of that are still here, at this conference, seeing the very beginnings of that. And we all have an opportunity to be just as big and robust and radical and audacious about this birth to three pieces the original concealers were about newborn screening. So let's be brave also. But we also have to be practical, so let's talk now about some of the existing programs outside of the newborn context that are worth thinking about. One of those obvious places we think about, when children leave the hospital we want to think about where well we find these children again? Really I think the most obvious place to think about is in healthcare settings. We think about, and a lot of people assume that children are being screened as a part of well-child visits, but as most of you probably already know, that is not happening, and it is not happening because of all of the long list of things the pediatricians already have to do there. It's not recommended in the bright Periodicity schedule. It is not recommended until children are four years of age. That is a potential venue that you could explore working with in your efforts to move forward, so that is one place you could go. Two other low hanging pieces of fruit are the early intervention part C program in your state. When you think about [ INDISCERNIBLE ] you have to remember that part C has an identification task and responsibility also. Now we found in our early data collection, that 20 years ago, and unfortunately this is still true, that many of the children identified with permanent hearing loss as a result of the screenings they received in head start programs that I will talk about in a minute, were already being served in part C early intervention programs and had not had their hearing evaluated. We have been down that rabbit hole multiple times, trying to understand what is an appropriate expectation of our community-based part C programs in terms of establishing the hearing status of children entering or being referred to part C, and the answer is anything but clear. That even though the requirement say a vision and hearing screening are part of the multidisciplinary evaluation, that is not necessarily happening, and if it is happening, often it is being done as a parent questionnaire, so there isn't necessarily a hearing evaluation done on children entering part C, even though the majority of those children are ending up in speech and language therapy without their hearing status identified, so keep that program in mind as a potential target for your next steps towards progress. That is a population that seems to have obvious written all over it as an area for improvement. Another program is Headstart. Now, during the plenary this morning, I was in the first session. There was someone who is that I still don't understand Headstart and what to expect about Headstart. Headstart programs, early head start in regular Headstart programs serve children birth to three in early Headstart, three through five and the other programs. All of those children are required to have a hearing screening every year, and fortunately during the last 20 years, we have been generously funded between [ INDISCERNIBLE ] HERSA to improve those screenings and incorporate them into Headstart programs. That is happening in many programs across the country. Not all, and I have a high turnover rate like we see in so many social services. So there is a need for ongoing training and technical assistance. But the beauty of these two programs is that on the books, they are committed to doing this, to identifying children, so they are obvious partners, and there's room for improvement and growth, so finding out if the status of what's going on in each of those programs in your state is worthwhile. Both of them have a requirement for screening. I'm talking about part C here. The same is true for Headstart programs. Each of them has a partner at the state level. Part C programs is federally funded directly's two states so there is a part C coordinator for each state. That would be an obvious person to get to know. From the Headstart perspective, they are funded directly too community-based programs with no state-level inter person at the top. But there is a Headstart state collaboration office that doesn't necessarily have any control over what he Headstart programs in their state do, but they are a collaboration entity and their role is to work with other state partners who need to and wanted to partner with Headstart programs in their state. So, meeting with those two leaderships in these respective programs would be a great beginning, and I will show you in a moment, we have created a couple of discussion guidelines that you could have with these respective potential partners. If we are going to sit down, what away and I talk about? Just to get those conversations started, so you can give those some thought. Individual health departments may have screening initiatives, school districts, home visiting programs and again, healthcare settings. In particular, community health centers have showed an interest over time. So you might want to consider them as a potential screening partner. Now, I started out by mentioning outreach. Just that awareness piece. There's a bunch of places that you could work with too just get the word out or that people understand, professionals and families alike, that hearing status in children is not necessarily a stable condition. And so helping the awareness of that be spread could be a useful beginning step, so we've got outreach as one of the ways that you could grow your EHDI program. We have activities that you can take and disseminate, and it wouldn't take much time to do that. One of the other things that you can do is to actually help programs planned to do screening.

You can guide them through some of those steps, some of the things they need to think about if they are going to get serious about doing screenings. We have resources to help you do that, to learn what questions to ask. There are checklists and other resources you can use to guide programs through that process. After you have worked with programs and getting ready to build a program, obviously there's going that is available as well, so you don't necessarily have to provide the training, but you can point people to quality training, and then afterward, help them find the T letter a that they need to maintain the quality of those screening programs, so kids hearing .org is where you will find a lot of that. That is where you'll find all of the early childhood resources that may be helpful in this. The leadership tools are right there. That is where you will see the second and third bullet right down there are the discussion guides for part C and Headstart leader conversations. I invite you to go and spend some time looking at these resources to see what's there. As well as all of the other resources for planning, training, practical tools for screening and follow-up resources. All right, we've got about five minutes left. I'm going as fast as I can hear. So the planet: You are all being expected to develop a plan and HERSA clarified some things for us. It is a plan. It is not about implementation. They want you to think practically but also imaginatively about was possible, and as you do that, take time. And this was reiterated to me just the other day. The part in red there to clearly detail what barriers or resource needs you will need in order to be successful. This is really a cool opportunity to be able to collect leadership no we can imagine this change. We can resist it, too. But we can imagine this change and we need to take out our ironing boards and iron out a bunch of wrinkles that are going to present as barriers, so describe what those are pure what are your resource needs? What do you think in my cost? Who do you think we need to have us onboard partners in order to take this on? the current EHDI system is not going to ever independently develop a birth to three screening program of all children in your states. I didn't do that with newborn screening either. We had lots of partners. Hospitals, for one. So as you envision that, think about who that is. It is more complicated, because it isn't just in one setting. One kind of setting. So take this as an opportunity to do that. These other considerations are on our website, so I encourage you to look at these if you are still unclear about how the plan needs to be constructed, but basically they are asking for comprehensive plan. It doesn't need to follow any kind of template or page limit or anything like that. Keep in mind that were talking about a plan for screening for permanent hearing loss, we are not talking about identifying temporary hearing loss. In this plan, we are to wrap up, what questions or concerns that I can adjusted our remaining remaining time that might help point you to other resources or support you may need? Anything? So remember to go to kids hearing .org. You can contact us through there and I can walk through any of these resources in detail with you. We spent a lot of time working especially with Headstart programs and I think are pretty confident about some of the elements that need to be in place to successfully identify children during this period. We are not just talking about just screening children characters number of folks out there who do health fairs and they screen a bunch of children, but they don't necessarily identify a lot of children, and we know about what needs to be in place an order to close the loop. And what partners have been particularly successful in doing that and why.

And sell, allow us to be your support and your help when it is appropriate for us to be there for you. You don't have to do this all by yourself. And thank you. Any comments or questions?

>> Do you know of any national best practice guidelines for the need for hearing test with the speech and language delay? I think you mentioned both part C and definitely doesn't have it, it is in there but it's not really something we can say it is best practice for every child with a speech and language delay to have a hearing test.

>> Like where is that written?

>> Area, I've looked at ASHA him and a lot of different resources to say ware is that best practice?

>> I don't know, it just seems so obvious, right? I don't know.

>> I just wanted to make sure I wasn't missing something with that. And then do you find that Headstart, they have to do screenings, but we have found there's not really any monitoring of that compliance, correct?

>> That's right. The requirement of Headstart is that they are to do evidence-based screening, and so it is incumbent upon the Headstart programs themselves to defend what they select as evidence-based peer fortunately, Headstart has given us the microphone many times to clarify for them that for the birth to three population it is OAE. If you want to try to defend something else, have at it, but you're not going to find evidence-based justification for anything else.

Anything else? Thank you, everybody, and thank you for all of your work for our kids.

[ APPLAUSE ]