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NCHAM

THE EVOLUTION OF EARLY HEARING DETECTION AND INTERVENTION PROGRAMS FOR INFANTS AND YOUNG CHILDREN: PAST, PRESENT AND FUTURE

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>> [CART ready]

>> Of course we always welcome those of you who have been around and there are various components of the system and they are players and some of the key issues. Today's webinar is the first in this EHDI newcomer series and if you were not able to attend the two previous owners for newcomers they were recorded, and you can check them out at infanthearing.org As well as this one was well done. the topics are covered were an introduction for new ideologists and today's webinar will place all of that in larger context so you have a good understanding of how the EHDI works and how it has evolved over time and the progress that has been made in the goals for the future that we are all working for; our presenter today is Dr. Carl White, director of NCHAM and NTRC, and Doctor White has been instrumental in developing the EHDI system since its very beginning all the way to this large national system we have today.

Note that today's webinar is being recorded so if anything disrupts your ability to fully participate today or if there are others whom you think of benefit from today's webinar it will be available to view them in a couple of days on infanthearing.org along with the others. I want to give a shout out to our captioner, that is a real person and we appreciate their ability and skills in helping us making the learning opportunities available. (Will set it longer thank you.)

>> without further delay allow me to introduce Dr. Carl White.

>> Thank you William and thank you to all of those who have signed on for this one today and am always excited talk about early hearing detection and intervention programs for newborn hearing; this little girl that you see on the screen is deaf. And she was identified when she was only a few days old and was given hearing aid shortly thereafter; today I want you to join me to learn how and why this is happening with more and more babies all over the world, it is a story of how science, advocacy, persistence and the condition of individual people can literally change the world for other people.

In the Great Book about how some ordinary people are able to do outlier things Malcolm Gladwell writes about success being a group project; he describes outliers in other words the 2-3%people that encompass more than is reasonable to expect and what most of us are able to accomplish, the success of newborn hearing screening programs or EHDI programs is a story of outliers and the story of people who did extraordinary things have changed the world I and nowhere is it more true than successes a group project than what we see in the development of newborn screening and intervention programs. As Gladwell says at the conclusion of his book, when outliers become outliers because of the contributions of lots of different people in different circumstances and today I will talk about some of those outliers and you will hear often in their own words what they did and why they thought it was so important.

So thus early identification of hearing loss really matter or is something to do because it has been done before? I hope that at the end of the webinar you will feel differently than this lady feels he will agree with me that it is an exciting development and we have done much but we have much more to do so let's start by talking about why it is so important. Permanent hearing loss occurs more frequently than any other condition from which we can screen at birth. If you took a random sample of 10,000 children born in this country you would get a distribution of congenital defects and diseases that looks like this and as you can see hearing loss occurs muscle frequency than other conditions such as down syndrome or PKU. And the fact that it occurs frequently underlines the importance of identifying it and doing something about it.

this is a picture of Helen Keller and Alexander Graham Bell with Helen's teacher, Ann Sullivan. Helen Keller was both deaf and blind and the spider that she became a world-renowned political and social activist and lecturer because she learn to communicate effectively, and it is this ability to communicate that enables her to do so much of what you did.

later in her life she was asked if deafness or blindness was the more significant disability for her; stop the video now.

And if you -- her answer revealed a lot about what we think it is so important to identify hearing loss early, she said that that this was by far the worst disability because blindness separates people from things but deafness separates people from people so this ability to communicate with people that lies at the heart of why we are so interested in early identification of hearing loss.

Children who are deaf and hard of hearing communicate in a lot of different ways as shown in this graphic; some use sign language, some use listening and spoken language, some use a combination often referred to as total communication; some use Cued speech; families are encourage to explore what will work best for them and we find that many families change their mind after trying one system, they will try something else for a while and that is okay what we think is important is that however families choose to communicate with the children, that they receive the support they need to communicate effectively and that support begins as early as possible.

I'm going to play a couple of examples of children communicating in different ways for a little bit of background so this next video clip is of two the voice who were adopted, and they were adopted into a home with the father is deaf and uses only American family which; the mother is hearing but American family which is among which of the home. They're leaving the car repair shop, start the video and the two boys are talking in the back of the van, or communicating in the back of the van. One little boy says the car is a high, going higher, hey dad, look over there, the car is moving up. There are many cars and there shaking.

Then he starts a side conversation, yes I love you and the mom signs I really love you as his brother watches the car. and the little boy looks over there as a drive along, an airplane and I see it, it flies. Hey dad, pay attention to me, his brother says what about trains? Trains go fast. I'm looking for a propeller, where is it? You mean the helicopter? Where is the helicopter? Up in the sky. Hmm, I don't know. Yeah, I don't know either, there was one there before.

What is remarkable about the little boy's conversation is not just labeling things that some people think about sign language; this video demonstrated sign language is a complete language, the boys are able to describe what is going on around them and they are able to recall events from the past, project into the future and all of that because they are in an environment where Sinai which is used frequently, and they were exposed to it early and they were able to become fluent.

Now, I'm going to play another video to give you a little on the Audio clip, a little historical perspective the classroom in the 70s whose families focused on listening and spoken in which an ongoing to lay a clip of the little girl in the class of represents about the best that we were able to do 35-40 years ago.

Listen carefully and see if you can understand what she is saying. Play that clip.

>> GIRL: (indiscernible)

>> That was very hard to understand, and I suspect most of you did not get it at this time I'm going to give you a visual clue. Play it again William,

>> GIRL: (indiscernible)

>> DR. WHITE: Now with the visual clue, most of you were able to understand most of what you are saying so put yourself in her place 40 years ago; she was able to communicate to some degree with family members who became accustomed to the cadence and the rhythm, and the tonal quality but for people outside the home it was like what you heard the first time, and so communication for children choosing listening and spoken language 35-40 years ago was often very difficult. This little girl have a bilateral severe hearing loss said you had a little bit of residual hearing, but it was still difficult.

I show that provide a historical perspective because this next video is of two little boys who have a much more hearing loss, profound hearing loss and they are able to communicate because of having cochlear implant in a much different way. Go ahead and play the video.

>> Hey, I'm AJ.

>> Hi, my name is Gibson.

>> People special and different ways.

>> One of the things that makes me feel special is I'm deaf.

>> I'm deaf too. Deaf means that your ears can't hear. AJ and I have special things to show you, called cochlear implants.

>> They help us. cochlear implant is a big word; C is for cochlear and the I is for implant.

>> See, it is amazing, like bionic ears.

>> My friends have bridges about my CI.

>> How does that thing stick to your head?

>> There is a magnet inside.

>> The magnet here connects to the magnet in my head.

>> the inside and outside have to work together; when I disconnect this I can't hear.

>> When it's on, voila! I can hear.

>> DR. WHITE: So voila! There is all there is to it. It is a fairly complicated. The procedure but thousands and thousands of children are benefiting from this.

All of these children, the little girls and these two little boys have severe to profound hearing loss but there are lots of other children who have mild or moderate hearing loss and I'd like to play a short video clip of two little girls with mild to moderate hearing loss, they are twins and both have hearing aids and were identified at birth.

>> Are you guys talking?

>> Weee!

>> Look this is the water. She's under water. Weee. Come on. Talk to me.

>> DR. WHITE: That is probably enough of that video William. The take a message from all of this is that how we go from where we were 35-40 years ago to where we are today? There are number of factors that have contributed to that. Certainly early identification of hearing loss is one of the primary ones. And as these videos have shown that is why it is so important to identify hearing loss early so children will be able to communicate, perform well in school and be able to access the world around them.

Fortunately while we were developing newborn hearing screening programs to identify the hearing loss technology was getting better and better; now for those children who choose hearing aid or culture implants those advances in technology are particularly important but for families to choose the American sign language the technology may not be as critical.

That is the third factor that we have learned about in the last 30 years, how to learn language? And how critical it is to start early and to provide fluent listening environments? For language.

Lots of different children with different levels and agrees of hearing loss are being identified now through the EHDI program. This slide shows how critical it is also to identify children who have mild and unilateral hearing loss. So this graph is a summary of five different studies; the greenish blue bars show the average achievement of children with normal hearing and the red bar shows the achievement level of children with unilateral hearing loss. And as you can see children with unilateral hearing loss even though they have normal hearing in one ear are significantly behind matched children with normal hearing by the time they get to the second or third grade. In fact that a time they are in the third grade the average child was unilateral hearing loss will be 24 months behind his or her peers in math, language and social skills.

We also have data now from a number of different studies showing that earlier results in much better outcome than later identification of hearing loss and this is a study by Mary Moeller at -- Hospital that compared children who were identified before six months of age to children identified after six months of age and as you can see those children identified earlier do much better.

So in summary early identification of hearing loss is important because it occurs more frequently than any other condition we have screened for at birth and we don't detect it early there are serious negative consequences in terms of language, Cognition , social skills, and if identified early there are dramatic benefits associated with early identification of hearing loss.

This is not new knowledge we have known this for many years, and this is a picture of Alexander and Irene Ewing, both educators from the United Kingdom who spent ways to identify ways to help children. During the next 50 years their little progress was made.

Prior to about 1990, we did have conventional auditory brainstem response; that was developed in the mid-60s to early 70s. We could reliably identify children who have hearing loss and the level of hearing loss. But even though auditory brainstem response was often referred to as ABR it was simply too expensive to do with all newborns. So even back then and auditory brainstem response this would cost $600-700 and people cannot afford to do that with all babies given the low incidence of hearing loss.

Because of that some people suggested we should identify high-risk indicators that made a child more likely to have hearing loss. Those were indicators such as low birth weight, family history of deafness, congenital infections and they did help. But the idea was to screen only those children with high risk indicators using ABR to make it more affordable. So about 10% of children had one of those risk indicators, the problem was that even when those systems work perfectly there were about 50% of children with congenital hearing loss who did not have any of the risk indicators and only about 2% of the children who had a high risk indicator had a permanent hearing loss meaning that 98% of young children with the risk indicator had normal hearing so even though it was better than doing nothing we missed most of the children with hearing loss and were testing a lot of children unnecessarily with the expensive ABR equipment.

About that same time starting in the mid-sixties and mid-seventies and number of countries started to implement behavioral-based screening which was only possible to do with children when they were 8-9 months of age so we missed those critical months of development but it was also very expensive testing to do and it took two examiners to visit the home, to set up testing equipment in the home and it took about an hour and a half to do the test and unfortunately children with mild and moderate and even severe hearing loss were often missed. So it was against this backdrop of not being able to successfully identify children in those years between 1950 and 1985, that we began to examine other ways of identifying hearing loss.

I want to pause for a moment to talk about how it was developed and give you two examples that I will come back to. The first was Isaac Newton a significant that many people identify as one of the finest scientists of all time and he wrote if I see further is by standing on the shoulders of giants, what he was able to accomplish was only as of what other people did and those of us who were seen this renaissance of early identification of hearing loss over the last 25 years need to acknowledge how many different people were involved in who some of the giants were.

Secondly, one famous scientist said give me a lever long enough in a place to stand and I will and identifying those levers move the world. The world for children who are deaf and hard of hearing is definitely moved, that will enable us to move the world will establish the foundation that will enable us to continue looking forward so that look at who some of the giants are.

I paraphrase Newton's words, by standing on the shoulders of giants we see further in some of the giants I'd to talk about for just a moment, first was -- Who took a particular interest in identification hearing loss, C. Everett Koop.

>> Mark Twain once said that even though people will complain about the weather but do nothing about it and until recently Twain's comment was substantially reminiscent of our efforts to reduce especially the age at which hearing impairments were identified; language developed so rapidly in the first years and the longer we take to discover problems the worse the outcome will be.

>> DR. WHITE: he identify the critical nature of identifying children early and being able to provide services that they need. Koop is a great user of the bully pulpit (sounds like) and did a great deal of moving people forward to recognize how important it was to identify hearing loss at an early age.

Second person like you like to refer to is Marianne Down, (sounds like) often referred to as the mother of newborn screening.

>> thank you so much. I can't believe, at 98 years of age I get a standing ovation for standing. I love every minute of it; and I love being 90. at this age you find that peer pressure drops a very rapidly. Anything I love was being able to watch the dream of newborn screening come true; I have on my office -- (indiscernible) that you don't find yourself out on a limb, here I am again.

remember that the next important thing is follow up an intervention and develop the finest intervention program that history has seen.

>> DR. WHITE: So Marianne talks about working together and she demonstrated tireless persistence and she talked about the importance of being willing to take risks.

The shine like you would like to refer to is David Kemp (sounds like), a British physicist who discovered auto acoustic emission and change the way in which we do newborn screening.

>> I'd like to show you this made in 1977. this is a little acoustic emission probe and it was effective.

>> We imagine (overlap speakers).

>> DR. WHITE: Okay, we're having a little technical difficulty without one that David was showing the first auto acoustic emissions machine that he developed back in the 70s; and it underscores just how important the advancement of technology has been in moving the field forward and I would suggest how important it will continue to be in the future.

The next giant I would like to refer to briefly is Doctor Lewis Cooper who passed away this past year. Lew for the president of the American Academy of pediatrics and did more than anyone else in pulling together the Academy to become a supporter and actually a promoter of universal newborn hearing screening.

Incidentally Lew is also on the team that developed the measles vaccine back in the 1960s and as many of you know measles before we could control the spread of was one of the primary causes for deafness. The development of the measles vaccine dramatically cut the incidence of congenital hearing loss.

The five giant I would like to refer to is Thomas Barron, with the Department of Education and maternal health Bureau, the man I often referred to as the godfather of newborn screening; he was the one that thought of the Rhode Island project and brought Dr. Koop involving convinced Lew Cooper to promote early detection of hearing loss to the Academy of pediatrics. Listen to what Tom has to say.

>> They had to (indiscernible) this crazy idea that Karl and I had to start the Rhode Island program; everybody was against this and thought we were crazy. But with their effort and continuous attendance to the task that is was happening now. As Marianne said there are many things to be done and I hope you are going ahead with that, because Marianne and I are going to retire slowly.

>> DR. WHITE: So Tom focuses on the fact that we need to not only were together, but we still have a lot of work to do. another talk about people who provided levers and places to stand and the first I like to mention is James Walsh, Congressman from the state of New York that created the funding program that we still have today that has enabled state programs to start and maintain early hearing detection and intervention programs, Listen to what he has to say about his work in that area.

>> I do lots of things in the job and I've enabled over many years to be successful in life of different ways, but this is probably the thing I care the most about and feel the best about.

>> DR. WHITE: significant that he said that of all the things he was able to do in Congress this was the one heap of his most important and I think he said it because he saw the impact it had on the life of children and families.

The next person is Doctor Betty Vohr and offers an important perspective as we think about what levers we need to use to advance newborn hearing screening.

>> I have learned so much along the way, probably the most important is from parents. I learned a great deal about being sensitive to the issues and having a child who is deaf and hard of hearing or being a parent who is deaf or hard of hearing.

>> DR. WHITE: So of all the things she did, Betty focuses on the importance of involving family and that has been a critical factor, and how families have been involved particularly in recent years.

The next person is Merle McPherson (sounds like) listen to her perspective.

>> hearing screening needs to be seen within the context of a much bigger agenda which is referred to as the 2010 agenda, very large. National agenda that have been put together.

>> DR. WHITE: So Merle recognize that for any program to be successful it have to be a part of larger program; they could not be a similar program and Merle's tireless support for newborn hearing programs over a 20 year period Brought us to the point where we are today.

And the final person is Irene Forestman (sounds like), the project officer for about 20 years for all the state-based early hearing detection and intervention programs. I put Irene up because most people have never heard of Irene that she was working behind the scenes she is one of those people we talk about this as being a group project and without people like Irene we would not be where we are today and she retired about four years ago and we miss her dearly.

So now, step back; we tried for 50 years after the Ewing’s first said we should do something about early identification about hearing loss and the next big breakthrough was from 1988 - 1993 when the federal government funded the Rhode Island hearing assessment project conducted by a team here at -- And of projects demonstrated we could do universal newborn hearing for the first time and that led to a consensus development conference in March, 1993 by the national Institute of health who concluded that all babies should be screened for hearing loss before they left the birthing hospital.

If you look at the journey that we have been on for 50 years at that point, it's a lot like one person describing life. Life is like an all-time journey, filled with delays, sidetracks, smoke, dust and jolts. Interspersed occasionally by beautiful this and thrilling bursts of speed, the trick is to be thankful that you can have the ride.

In the period of 1998 - 2000 we had one of those thrilling bursts of speed and during that time there were a number of publications about the benefit of early identification like by Christy Yoshinaga-Itana, Moeller, Mehl, Thomson and others. also many states began to pass legislative mandates and at this point there are 43 states that have legislative mandates and by the year 2000 during the two-year period There were 27 different states the passed it which made a difference as we try to develop a national program. Also the national Academy of pediatrics under the leadership of Lew Cooper published a statement about the importance of early hearing intervention and Congress passed the Walsh bill and money became available to the Centers for Disease Control.

We were able to take the percentage of screenings in 1993 was about 6% but by 2004 we had increased that to the lower 90%; we're now screening 98% of all babies born in hospitals. the average age of identification in the 70s and 80s and early 90s or in the published reports was 2 1/2 - 3 years of age and by the 90s, early 2000 we reduce that, making a huge difference for children could benefit from technology and learning sign language start early identification lead us to that point.

We look at the Centers for Disease Control data reported each year from the states EHDI programs and have gone from identifying 855 babies in the year 2000 to 6432 in 2018. We need to do a better job of identifying babies who have mild hearing loss; but the progress you see here shows how EHDI programs are continuing to mature and continuing to become better and better. Some of you watching this webinar have never seen the baby screen; I'd like to play a brief excerpt of this video that we developed to use for parent education classes which shows just how simple the screening is. Go ahead.

>> Sofia?

>> Hocking your baby's hearing be checked? Thanks to advances in technology we cannot check a baby's hearing shortly after birth and the staff is concerned about your newborn's hearing because one out of every 300 days is born with hearing loss in children who cannot hear clearly will have trouble learning to communicate and this is why it is important to check your screen each newborn's hearing using simple and painless procedures.

One is called OAE, auto acoustic emissions, he puts in the near a sound making device and produces emissions analyzed by sound screening equipment and the other method is AABR, automated auditory brainstem response and the person places Band-Aid sensors on the head, and the sensors analyze the brain's response to the sound. No matter which method is used in a few minutes the screening is finished and the result is displayed.

>> DR. WHITE: So the process of newborn hearing screening in a hospital setting really does take just a few minutes as you see here and that equipment and getting better and better and because of that we are able to identify children at very early ages.

Now as the EHDI system has proceeded to grow and to improve it is becoming more and more clear that what Malcolm Gladwell said about outliers is correct. It really is a group project and at the center is always a child in the family and also the primary health care provider; those other two units that need to work together most closely to bring all of these other groups on board to make early hearing protection and intervention a success.

One of the things that is very important to remember in all of this is that children who are deaf or hard of hearing are a very heterogeneous group and this pie chart shows the degree of hearing loss for children reported to the CDC from the state EHDI programs; as you can see, some of them have severe to profound hearing loss, some bilateral profound and almost 40% have unilateral hearing loss and another 14% half bilateral mild hearing loss and those children with unilateral and mild hearing loss are just as important to identify as are the children with bilateral profound hearing loss.

To have the EHDI system working like it needs to work, we need to make sure we are addressing all of these children. Many people think about hearing loss as a dichotomy. In actuality there are many different dimensions so there is sensorineural loss is conductive loss, congenital versus acquired, progressive versus nonprogressive, some is tied to genetic mutation. we need to address all of these different types of hearing loss.

This graph shows that most families who have a child identified as deaf or hard of hearing are surprised by that outcome. 90% of all children who are deaf or hard of hearing according to a survey by University Gallaudet University come from a family where both parents are hearing; only about 5% him from families where both parents are deaf or hard of hearing. And since language develops mostly in the home, it is absolutely critical that the families choose to have American sign language, and that it begin early, and the family members become fluent in American silence as well so the child can have that role model.

Recent data shows that families continue to choose different options for communication; and that is a good thing. About 60% of families -- 66% are choosing listening and spoken language, 6% American sign language, 12% cued speech. it is also important to underscore the fact that families may choose listening and spoken language to start with and may switch or add American family was later. There is no single or correct decision; the important thing is that they receive support in the coming flowing in that communication model and families may choose to change their mind when the child is 2-3 years old and they continue to receive support.

As important as the newborn hearing screening is this cartoon underscores that we still have work to do. It is not just a matter of implementing a somewhat collocated universal cure and project and having a miracle occur and then a successful outcome for the child. As this person points out, we need a little bit more work. There is also a diagnosis, medical intervention, program evaluation and family support it needs to be taking care of. These components of a successful early hearing detection and intervention program of course start with the screening which has established by the maternal health Bureau and the Center for disease control should always happen before one month of age and if the child has not passed that screening they should be diagnosed by the time they are three months of age or before; they should be referred to an early intervention program by the time they are six months of age or before.

I like to say that the real goal should be one week of age for screening, three weeks for diagnosis and six weeks for intervention because the earlier we start this process as noted by Doctor Cooper, the better the outcomes are for children.

all of this have to happen in the context of the child's medical home, the child's primary health provider who can help to coordinate and make sure the child is receiving the assistance that they need in conjunction with the child's family.

all of that if it is to be successful have to be part of the system that keeps track of when the children are screened, when they are diagnosed, they are able to track children for the process to make sure that they receive the assistance that they need at the right time.

And that Should be done in a way that program evaluation and quality assurance is a continual part of the program. We still have a lot of work to do to improve these programs to the point they need to be, and everything should happen in the context of family support.

the reason we do all of his work is so that we can enable families to be more successful; and the reason that it needs to happen quickly is that we can maximize the growth that they child makes. Listen to what one parent have to say about how important it is to do this in a timely manner.

>> Early identification meant for us that time was on our side; we have the time to make choices about communication styles early so time was given to us that is stolen from other families merely because they don't have the child screened.

>> DR. WHITE: So in her case, the outcome was good and as she said time was given to us that was stolen from other families.

I'd like to talk now about six areas that we still have work to do, the first is this chart from the American Academy of pediatrics, you can't read it for the part I want to focus on I've highlighted here; the American Academy of pediatrics recommends that all children diagnosed with hearing loss from newborn hearing screening programs receive an ophthalmological and genetic evaluation to make sure that there are no other factors contributing to that hearing loss.

We did a survey in 2006 and another in 2012 which was the same question. Where we asked and national group of pediatricians and family practice physicians that if they had a child for whom they were caring who was diagnosed with a moderate to profound bilateral hearing loss, to whom would recommend that baby be sent? Alarmingly less than 1% of them identified the ophthalmological evaluation is one of the things that should happen. Only about 9% identify the genetic evaluation; 75% said they would refer the child to an otolaryngological evaluation.

We have a lot of work to do to educate physicians; and in that same survey we asked decisions when an infant can be fit with hearing aids and the answer as you saw in the first light of this presentation is during the first few weeks of life, we can put hearing aid some babies appropriately.

According to the responses from that survey almost 40% said you cannot put hearing aids on babies until there six months or older, so we have a lot of work to do.

The second area we need to work on is improving loss to follow-up, both on the screen program to the diagnostic program and to the early intervention program. This shows that we have been making steady progress over the years, but we still have a ways to go.

This chart shows the percentage of babies that are identified and are loss to follow-up; If there are 10,000 baby screened, 990 of those, 9,990 will receive the services that they need but we do need to improve the loss to follow up between babies who are screened and fail and receive the diagnostic evaluation.

The third area we need to work on is emphasized well by Bob Cicco. Could you play the video for us William? Maybe not.

>> When we did a screening in the newborn period Our overall goal is to take that age when children were diagnosed with hearing loss which used to be 18 months to 2 years, down to the earliest as possible when we know that intervention can in fact make a difference. One of the potential risks that we run into that we need to overcome is making people feel that just because they passed their hearing screening as a newborn that they have never had a concern about hearing the rest of their life. You would think that people would understand that and it would make sense to people but I will tell you that when I go and talk to physicians’ offices, I get asked the question, do that has a newer screening does that mean I do not have to worry about screening? Yes, you need to worry about hearing because there is progressive loss and acquire loss of the need to continue to be keyed on throughout the child's life.

>> DR. WHITE: So I can't emphasize enough how important it is to recognize that because the baby passes and newborn hearing screening that does not give them a free get out of jail card. NCHAM has been very active for the last 20 years in working with Headstart programs and others to identify children in that young, early childhood period. In 2001-2004 we conducted a study with about 3000 children in which we identified about two children per thousand with permanent hearing loss; another 20 per 1000 with transient losses, and those programs have been disseminated across the 50 states and we are making progress, but we still have a lot of work.

This chart shows the incidence of hearing loss among young children; the CDC is reporting about two children per thousand with permanent hearing loss in this shows that there are 2-3 times that many for children 6-19 years of age.

The fourth area we need to improve his use of tele-intervention to provide services to families; the Covid situation is emphasize how tell intervention can be used. I'd like to play a short video clip of the family receiving tele intervention for a child who is deaf. Go ahead.

>> Hi!

>> Hi Alex.

>> So why don't you present the sound Nancy and we'll see if he has any reaction to your voice.

>> No toy?

>> Present the sound first and let's see if he turns to you or anything like that.

>> Ahhh ahhh!

>> Perfect. Awesome.

>> Yeah! Ahhh ahhh. Need a toy?

>> He looked up.

>> Ahhh ahhh -- He's never done that before (imitating mother.) That's the first time I've seen that.

>> That's great.

>> DR. WHITE: The power of tele-intervention is that it would can help the parent understand how to interact with your child on a daily/ hourly basis in the home that instead of having an early interventionist coming in once a week to work with each other for an hour the child is receiving the kind of linguistic relation and support all during his/her waking hour.

more information about how to provide tell information is available in our website at the Tele intervention research guide.

Another area where work needs to be done to us in the identification and treatment of children who have congenital cytomegalovirus virus; a virus that is very frequent which in most cases does not do any damage but if the mother contract the virus when she is pregnant it can have long-lasting negative effects for the baby and a little less than 1% are born with this congenital CMV, about 30,008 year and about 5000 of those babies will be deaf or hard of hearing by the time they reach preschool. There are other Serious complications as well. unfortunately most people do not know about CVL; this comes from a survey done by the CDC that shows that the percentage of people who are aware of cytomegalovirus is much less than the percentage of people who are aware of other conditions in another incidence of cytomegalovirus, and fortunately the negative consequences can be substantially mitigated through basic hygiene practices and being careful about how you interact with your children. So NCHAM is putting a lot of work and many state programs are now screening children who fail their newborn hearing screening for congenital cytomegalovirus as well; unfortunately the Covid-19 and then it is interfering with that but when we get over Covid will continue to work on that.

Finally an area that has great potential to the identification of genetic mutation; We are proposing that removed to a screening protocol where instead of just doing a physiological screening in the hospital we also screen all babies with the testing is we are doing but we also add to that genetic screening and congenital cytomegalovirus screening and that is not yet been accomplished by the technology is certainly there and we are beginning to do it in a pilot effort in some hospitals; I think this is an area where you will see real progress during the next five years.

Last slide, many of you are familiar with Lily Tomlin from Laugh-In, the popular show several they get to go. She once said, I always wondered why someone didn't do something about that, then I realized I was somebody.

My goal in this presentations as many of you are new to the EHDI program is the layout not only where we have come from and how much is been accomplished but also to emphasize that there is still work to be done and that just as newborn hearing screening up until now has been a group effort and that is why it has been successful and why I showed you some of the people that have been so as to mental in making that successful I wanted to emphasize that there is still work to be done at I hope that you will look at what your role is, whether professionally employed in an area related to early hearing detection, whether you work for an advocacy agency or someone who is deaf or hard of hearing yourself. There are lots of opportunities to continue to improve where we are and by doing that to enable more and more children to have the benefits of mentally early identification but excellent services.

So thank you for coming today and participating in this. We ran a little over time, but we may have time for a few questions, and I'll let William moderate that.

>> Thank you Carl. That was an excellent overview and so helpful. If some of you need to run off before you do you give us some feedback and Dr. White agreed to stay little longer to answer questions and we will do that for a few minutes. The first one Carl is can you, verify how the intervention piece of EHDI, the "I" in EHDI, overseen by -- relates to part C, which is overseen by the office of special education programs in the Department of Education?

>> DR. WHITE: That is a great question. EHDI stands for early hearing detection at intervention; the intervention part of EHDI is to refer the child who has been identified with hearing loss to the part C programs. Part C is a part of the individuals with disabilities education act which is the federal law that provides funding and guidelines for children who are disabled.

So children with hearing loss would fit into that category; the actual intervention programs themselves are overseen by the Department of Education within each state by usually a Department of Education or a Department of Health. But it is a completely separate program from the EHDI program. EHDI focuses on identification and referring and part C of IDEA focuses on actually providing the services to the children or you might want to think about it as EHDI identifies the children and delivers them to the doorstep of IDEA. And IDEA has funding both state and federal and has guidelines to provide the services that those children need.

EHDI has resources mostly from the states with some federal to deliver services to their doorstep and part C exit up at the doorstep and start providing them with services.

>> WILLIAM: The next question Carl is, what stands out for you as some of the most significant new components of the reauthorization of the EHDI act of 2017?

>> DR. WHITE: Great question again. The reauthorization of the EHDI in 2017 was a federal law that does not require newborn hearing, it never has. The federal law provides resources and guidelines to assist states and state legislators in 43 different states have passed legislation requiring new board hearing screening and those states that have not passed legislation are all doing that even though they don't have a legislation but the requirement to do screening is a state law, but the requirement is a federal law. The federal law was first passed by James Walsh back in 2000; since that time federal laws have to be reauthorized periodically and the most recent reauthorization was in 2017 in that reauthorization added to the guidelines for what state should be doing, the screening identification of young children. So up until that point it was focused only on newborns; but 2017 expanded that to include young children up to age; most people estimate that twice as many children acquire hearing loss during those early childhood years as are born with hearing loss and yet right now state EHDI programs are focused mostly on the newborns because it was not a part of the federal law before. Now that it is states are beginning to expand into that more and more and I see that as one of the big changes that will happen over the next three years.

>> WILLIAM: The next question is, there are several assessment procedures for newborn hearing screening, ABR and OAEs; Do you think behavioral observation place a critical role?

>> DR. WHITE: behavioral observation plays a critical role in the diagnosis after the screening for newborns so you have to separate early diagnosis; for screening children the OAE and AABR (sounds like) are excellent tools, a little like arguing whether a Mac computer or a PC computer is best, they actually both work very well and each have their proponents and some people are quite enthusiastic about one versus the other. But about half the country uses OAE and half the AABR; for children themselves they are not yet capable at 1-2 days of age to respond or behavioral observation in any consistent way and of the children get older than behavioral observation becomes a very important part of the diagnosis process. It's most effective after children are about 6-9 months and if you are identify children in the early age that data we have available shows that (indiscernible) are much more cost efficient and much more accurate in screening them during that childhood period That begins when you come to fitting hearing aids on the child and doing the final diagnoses than behavioral observation plays a very important role.

>> WILLIAM: We have time for one more question. Can you talk about any efforts that are beginning to be made to ensure that vision is also included in early identification of our children? And how this will assist with the edification of children who are deaf/blind.

>> DR. WHITE: Yes, so blindness or vision impairment and hearing loss are what is often referred to as co-morbid; children who have a higher incidence of hearing loss have higher incidence of vision loss in both the critical to identified as early as possible and provide assistance as early as possible. The technology for screening hearing loss is further advanced than for identifying vision loss in newborns but there is a lot of work going on and we are seeing progress made. I think it's very important for children identified with congenital hearing loss that their vision be monitored very closely and on the other side of that coin, children who are identified with vision loss during the first few months of life, that you be sure to monitor your loss even though they passed the newborn hearing screening as was pointed out by Bob Cicco; it does not mean that they can't acquire here a lot later so it is very important for those two programs to work together much more closely than they have in the past.

>> WILLIAM: Carl, thank you so much for covering such a lot of territory today and thank you for all the question answers as well as all of you who attended today. This webinar has been recorded and will appear on infanthearing.org in the next couple of days where you will also find the old videos of webinars that are part of this newcomer series as well as other webinars that we have offered in the past. Get acquainted with infanthearing.org where you will find a wide range of resources that will support your efforts in whatever capacity you are functioning to support the EHDI system in your respective states.

Thank you to our captioner for your services today, and today everyone. Remember to click on the screen where you see the arrow pointed to give us an evaluation feedback and if you want you will also be able to get a certificate of attendance at that same link; thank you.

>> [End of event]