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National Center for Hearing Assessment and Management - NCHAM  
Meeting the Needs of Physicians in Support of EHDI  
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>> MODERATOR: This is an audio check for today's webinar entitled "Meeting the Needs of Physicians in Support of EHDI."

We'd like to know that our technology is working and you're receiving the webinar. If the audio is not to your liking, you'll want to adjust that on your own headset or speakers. If you're experiencing a fragmenting to the audio signal, that's probably related to your own connection, and you may need to sign off and come back on, and hopefully we'll have a better high-speed connection.

It looks like the majority of you are letting me know that you're receiving either good or excellent transmission, and that's what we want to hear. For the few of you indicating otherwise, try adjusting the volume on your own end, and hopefully that will solve your problem.

We're going to be starting in about five minutes at the top of the hour. Today you'll be able to communicate with our presenters through a Q&A field on screen and you don't need to worry about a microphone for today's session. We'll be starting in five minutes at the top of the hour. Thank you for your feedback.

We want to welcome you to today's seminar. While we wait to get started, there's a poll question to complete. We'll be starting in about two minutes at the top of the hour. You can adjust the volume of your headset on your end to your liking. You will be communicating with today's speakers through a Q&A screen that will be presented at the time the presenters open it up for questions and answers, so you should not see that screen at this time, so don't worry about that. Thanks for communicating your primary role so our presenters have an idea of who is joining us today. Again, we'll be starting in just about a minute or two.

I believe our presenters are ready to go. Can we do one last audio check with our presenters? Diane, can you introduce yourself briefly?

>> DIANE BEHL: Certainly, and I'm Diane Behl from the National Center for Hearing Assessment and Management.

>> JACK LEVINE: Hi, this is Jack Levine, a member of the EHDI leadership team from the American Academy of Pediatrics.

>> MODERATOR: And Dr. Karl White?

>> KARL WHITE: Hi, this is Karl White. I direct the National Center for Hearing Assessment and Management.

>> MODERATOR: I'm going to initiate the meeting and turn it over to our presenters. Today's meeting webinar is now being recorded. Diane Behl.

>> DIANE BEHL: All right. Thank you, William. Good afternoon, everyone. And welcome to "Meeting the Needs of

Physicians in Support of EHDI," part of the NCHAM Webinar Series.

Again, with me today are Dr. Karl White, and Dr. Jack Levine, a fellow of the American Academy of Pediatrics and a member of the EHDI team, and I'm Diane Behl, a senior researcher at NCHAM.

Again, just to remind you after the presentation, we'll have an opportunity for you all to pose questions and comments, and that will be in the form of the chat box that will appear on your screen on the left-hand side. So you will not need a microphone for today. All right.

Let's get started. As most of you know, judging from the list of attendees, to achieve EHDI's 1-3-6 goals of achieving complete hearing screening by one month, diagnostic test by three months, and intervention, including amplification by six months, a team is needed, particularly with the medical home.

Let's look at the medical home with regard to coordination, communication, and access to EHDI systems. They have a critical role in making sure that has occurred, that families are connected to diagnostic services, if needed, that that information is being reported to the EHDI system. Medical homes connect families to needed specialists, to early interventionists and family support services, and also, they play an important role in early childhood hearing screening later in life.

So given this critical role of the medical home, NCHAM conducted a survey with help from Boys Town as well as the American Academy of Pediatrics. The purpose of this survey that we did in 2012 was to understand the degree to which American homes are engaged in the EHDI system.

Second, we want to update our knowledge of physician attitudes and knowledge regarding EHDI and in particular assess how much progress has been made since a similar survey was administered in 2005. And ultimately, we felt this information could be used to drive strategies to support the role of physicians in EHDI.

Let's take a look at the methods we used. First, NCHAM sent an invitation to all state EHDI coordinators, explaining the purpose of the survey and asking if they were interested in participating. 26 states participated, which results in over 2000 responses. You can see the states that participated here in the survey here in green. The EHDI coordinators were responsible for identifying the physicians who care for children in their states, and they often came up with this list with the support of state AAP or the American Academy of Family Practice chapters.

All physicians received a hard copy in the mail and a link to a URL if they preferred to answer online. Call sharing was used with NCHAM covering the cost of the materials and doing the analyze, and the states covering the postage and the labor to do all the mailing.

Here you have a view of the characteristics of the respondents. You can see in blue the characteristics of the survey from 2005 and then the characteristics of those in 2012. As you can see, there was roughly some good comparability in terms of what the demographics looked like. We had roughly over -- slight over half were pediatricians with family practice and otolaryngologists and neonatology. The primary area was a metropolitan area with slightly under half in smaller areas.

Over 80% reported that they practice in private practice or in a community clinic, followed by hospitals, a small portion in medical schools or universities or others. And we had just slightly over half the population of physicians were male.

Now, I also would like to share with you the results from the survey, but actually, I'm going to pass this on to Karl to tell you what we learned from the survey. Karl?

>> KARL WHITE: Thanks, Diane. Because physicians are such a key part of the EHDI team, this survey was designed to find out how much they knew and what kinds of things they were doing, and some are their opinions and attitudes about key aspects of the EHDI process.

So one of the questions we asked is how often they were getting results of the hospital-based screening because for the physician to be able to do something about it, they needed to know what happened. And we found that only about 80% in both 2005 and 2012 indicated that they were getting results, so that was the mean. A little encouraging that 99% is the median, so it says that over half of them are getting most of the results, but there's still a gap in terms of physicians being notified as to what happened during that newborn hearing screening process.

We also asked them how much trust they had in the newborn hearing screening results and this bar in the middle suggests that more than half, half to three quarters of the physicians, have some concern about the accuracy of the newborn hearing screening results. Hasn't changed much since 2005. We do see down here that those physicians that have seen more than 25 children with permanent hearing loss in the last five years or the last three years have a little more confidence in the screening results than those that have seen fewer children. So that's a good sign, but it still suggests that we have a ways to go to help physicians understand how trustworthy these results are.

In terms of how often they connect with the state EHDI program, we asked it in two different ways -- how often do they receive information from the EHDI program, and how often do they send information to the EHDI program. So over half of them are saying that they never receive information from the EHDI program. Now, that suggests that the initial slide I showed you about how many receive the screening results, that they're getting that often from the hospitals, which is a good thing. But we would hope that physicians are in frequent contact as needed with their EHDI program, and particularly in terms of sending information into the EHDI program when additional hearing screening results are collected or with diagnostic results are collected or when children are enrolled in early intervention programs, that would often be the primary care physician who would know about those things, and it's important for the EHDI program to receive that information. So the fact that two-thirds of the physicians say they don't ever send information to the EHDI program is a person. Now, this question wasn't asked in 2005, so we don't know whether it's changing or not.

In terms of their knowledge of when children can be fit with hearing aids, when they can be enrolled in early intervention programs, when they can be diagnosed as having a hearing loss, we ask this question with an open-ended question. So we didn't want to give hints as to when it would be by giving a multiple choice. So, for example, we just had an open-ended question who said, how old is a child when they can be diagnosed with a definitive hearing loss, or how early can a child be fit with a hearing aid. And the results were concerning. In 2005 there were 47% who knew you could fit a child with hearing aids as less than three months of age. Now, many of you on this phone call, because you're heavily involved in EHDI programs, would know that the best answer is less than one month of age. We want to get hearing aids on children whose parents choose that option as early as possible, and certainly, there's nothing preventing us as fitting a child as less than one month of age, but even if we expand that to three months of age, in 2005, there were less than half that knew that was possible.

In 2012, the numbers are actually a little bit worse, probably because of the differences in how the sample was composed, but these data are pretty convincing that we're not making progress with respect to physicians knowing how early we can fit the children are hearing aids. And we see similar results on the other questions. For example, how old can we diagnose a definitive hearing loss. It was 52% in 2005 and 58% in 2012. So we still have a lot of education to do in terms of

physicians understanding what's possible with a child who has hearing loss.

Now, the American Academy of Pediatrics has been active for a long time in trying to educate their members, and this was developed ten years ago and one focuses on what other medical evaluations children who have been diagnosed with hearing loss should receive. So as most of you know, I'm sure, through the Joint Committee on Infant Hearing and through the American Academy of Pediatrics, it's recommended that they receive testing, and we asked, if you had a child who was diagnosed with a permanent hearing loss, to whom would you refer the family? To what other specialist would you refer the family?

And as you can see, on this one, we haven't made progress from 2005 to 2012, only 9% of the physicians said that they would recommend a child diagnosed with a permanent hearing loss to a geneticist. Only 1 to 2% said they would refer to an ophthalmologist, so we have more work to do with what the next steps would be.

We also asked them what conditions would put a child at rescue for permanent late-onset hearing loss. Now, this comes from the Joint Committee on Infant Hearing. All of you all know that there are risk factors listed in that JCIH statement. Here it wasn't an open-ended question. We listed each of the conditions, and those familiar with the JCIH conditions would know there are some in here that we don't have any evidence puts a child at increased risk. If you look at those indicated here with the red arrows, they are all conditions that do put a child at increased risk and most of the physicians realize that those put a child with increased risk with the possible exception of congenital syphilis. But when we had the distracters there, we still had 20 to 25% of the physicians choosing those as something that might put a child at increased risk.

We asked the physicians whether their training had adequately prepared them to meet the needs of child with permanent hearing loss, and only 18% in both 2005 and 2012 indicated that they felt their training adequately prepared them. So this is an area where we clearly need to do more work, and it's an area where we could have the biggest impact. If we could do a better job of getting medical training programs to devote more time to hearing loss, that would probably have the greatest impact. But you also have to keep in mind how many different conditions physicians need to be educated about. So the typical physician will only see two or three or four children with permanent hearing loss in their entire career. So it's -- it's a challenge, and we need to find ways do just-in-time learning as well to incorporate training into the medical school training.

A lot of progress has been made in the last 20 years with cochlear implants. You see a lot more popular press information about cochlear implants, so they're becoming better known in the community at large, so we were curious if physicians understood who would be candidates. Certainly, those with bilateral profound losses are candidates. This is still a parent choice issue, and we're not saying that all children should have cochlear implants necessarily, but there would be some noticeable progress of physicians recognizing that.

However, if you look at these other categories, children with bilateral mild to moderate losses are not candidates for cochlear implants and the fact that we have 26% of physicians saying they would be candidates is concerning. Part of this growth may just be due to the fact that in the general public there's more awareness of cochlear implants. Similarly, children with unilateral mild-moderate losses are definitely not candidates for cochlear implants but yet 10 to 12% of the physicians indicated that they were.

This last category is a little more ambiguous in the sense that, although the FDA guidelines would not say that a child with a unilateral profound hearing loss is a candidate for an implant, we are seeing some movement in that direction with off-label use of cochlear implants, where parents are asking for them with children who get unilateral profound losses, and occasionally we do see children with unilateral profound losses being implanted. So this isn't necessarily wrong, but it would be -- it's still unusual for those children to receive cochlear implants.

So the take-home message here is that physicians are not as well educated as who are appropriate candidates as we would like to see.

We asked them how confident they are in talking to the parents of a child with a permanent hearing loss about these various situations, and there is a lot of data here. I won't take the time to go through all of it. But, for example -- actually that highlight is in the wrong place. I meant to highlight the causes of hearing loss. So the causes of hearing loss would be related to the risk factors I showed you just a moment ago, and as you saw there, there are a fair number of physicians who don't understand what the risk factors are that contribute to hearing loss, but here it says that almost 80% of them, 90% of them, are very confident about what the causes of hearing loss is, which isn't consistent with the other data. So one of the concerns raised by these data are that if you have people who are very confident who don't know what the correct answer is, that's even worse than having people who aren't confident not knowing what the correct answer is.

We asked them which of the following -- unilateral losses versus mild bilateral losses versus moderate and bilateral losses or severe profound losses -- contribute to difficulties with speech and language development. It is encouraging to see that better than 95% of them understand that moderate bilateral and severe to profound bilateral have an impact on language development. It's concerning that only 72% of them realized that unilateral has an impact on speech and language development. So a quarter of physicians still need to understand that.

We asked how often they were doing hearing screenings for infants and young children in their office. 28% are doing screenings, which is encouraging. We didn't ask this question in 2005, but the sense I have is that this is increasing. That's partly why the American Academy of Pediatrics has addressed this question in recent years. But when we drill down further with this question, there are some concerns here as well. One of the questions we asked is who they were screening. 28% said they were screening babies who didn't pass the newborn hearing screening test in the hospital. This could be good if those hospitals are reporting back to the EHDI program, but as we saw earlier, a fair number of them are not reporting back. 81% of them are screening when their parents voice a concern about the child's hearing. We would hope this would be 100% instead of 80%, but it says that most physicians here are doing what we hoped would happen.

As we drill down a little further and ask them how often they use the various instruments or approaches for screening children, there are some concerns here. So what we would hope that they would do -- be doing in that office visit is some sort of -- of a physiological nature, such as OAE, only about half of them are frequently or always using OAE. It's understandable that they aren't using automated ABR because as a child gets older and wiggly and more active, it's more difficult to use automated ABR. It's not impossible, but it's more difficult, and that doesn't surprise us. The fact that 55% are using response to noise makers and almost 80% are using caregiver interviews or questionnaires frequently, you know, if they were using these questionnaires in conjunction with OAE, that would certainly be appropriate, but the fact that only 50% are using OAE but close to 80% are using interviews or questionnaires suggests that in many cases, it's the caregiver interview or questionnaire which is the sole method. So as more and more physicians do screening in their office, we need to make sure we're helping them understand what is effective and training and support to use those tools as well.

In their offices with the screening that's happening, about half of them are doing it with nurses, about 20% of them are



doing it themselves. So this suggests that they certainly have interest in this and we just need to help them acquire better schools and procedures.

In drilling down a little further with the data, we looked at whether those physicians who were seeing more children with permanent hearing loss had different responses on some of the key questions. So what I want to compare here is those that are seeing -- had seen 50 or more children with permanent hearing loss over the last three years, what that suggests is those physicians have either advertised themselves as having a particular expertise in that area, or word-of-mouth advertising has gotten around through the audiologists that these are two you should go to if your child has a hearing loss. If they would routinely recommend a child to a geneticist goes from 4.8 up to 50%. Now, 50% is a lot better than 5 or 8 or 16%, but it's still only 50%. What we would hope is that this would be 100% for all physicians. These data suggest that those physicians who see the most children do better than those physicians who rarely see a child, but it still says we have a lot of work to do. And the same is true with these other questions. Whether you can fit children with hearing aids under three months of age. Two-thirds of the physicians that see lots of children, but only a third of the physicians who don't see very many children. So we're moving in the right direction, but we still have a long ways to go.

In looking at what correlates with what the best practice knowledge is about hearing loss and treatment, the slide I just showed you shows that there's a substantial relationship on the number of children being seen. We did similar analyses on other variables. I won't go into those. But the take-home message shows that those who thought they had good training did a little bit better than those who thought they had not had good training. Those who had been practicing pediatrics for a long time did a little bit better than those who had been practicing it for a short time. We expected just the opposite here, really. We were hoping we would see that the younger physicians who had been more recently trained would be getting better training, and it wasn't a large effect, but it was just the opposite of what we were hoping to see.

There was a small positive effect associated with the percent of the practice that was comprised of birth to five year Olds, so lots of pediatricians see those as well, so there was a focus on those with the younger children to get the answers a little more correct than those who focused on older children. So the take-home messages from the survey, there are certainly lots of them, but if I were to pick out six take-home messages, it would be that most physicians are getting the newborn hearing

screening results, but there's not much other communication that happens with the state EHDI program.

There's some skepticism related to how trustworthy newborn screening results are, so we have to do a better job of helping them to understand that.

We haven't made progress in terms of their knowledge concerning when babies can be diagnosed, when they should be referred to early intervention, when they can be fit with hearing aids, nor have we made progress in better understanding the risk factors or the causes of hearing loss.

Most, in 2012, felt unprepared and actually a few more than in 2005. And finally, that we've got a significant number of physicians who are now doing hearing screenings in their office, but many are not using the right tools to do the hearing screening, so it's not as effective as it could be. So there's still a lot more work to do. Diane?

>> DIANE BEHL: Thank you, Karl. Given the importance of this information, one of the things we recently did was send an e-mail to state EHDI coordinators asking you how you use this information. When we analyzed the data for the participating states, we sent them reports that said, here is a summary of your state-specific results, and then we also allowed them to compare to the cumulative national perspective. So here's an opportunity to share some information or think about how it can be used to improve your EHDI program. And so what we have here are some ways that EHDI coordinators reported using their information. For example, to raise awareness, sharing examples with your state EHDI advisory board or something that can be presented at ground round, at physicians conferences, as audiology task forces.

Number two, it can be used to educate or provide resources for physicians to improve their knowledge and practices. For example, states have been engaging their chapter champions in training, taking a look at perhaps their loss of hospitals with -- a high loss of follow-up rate and how that maybe can say, can we better support our medical homes in that area by providing these sources. And some states have also done some follow-up surveys to drill down, perhaps, to interview physicians and learn more, and some have even told me that they're interested in repeating the survey themselves.

Third, it can be used to guide your policies and practices. For example, there's a lot of efforts going on in quality improvement right now in regard to EHDI. This is a great opportunity to target physician behaviors. It also can be used to guide interdisciplinary training which is important for that collaborative approach to EHDI.

At this point I would like to turn the presentation over to Dr. Jack Levine. Dr. Levine is board certified in developmental pediatrics and who is passionate about the role of the medical home in EHDI. Jack, I'll let you proceed.

>> JACK LEVINE: Thank you very much. Actually, this is, I think, the third time I've heard this information presented and I'm still like totally befuddled by the results and what it means to primary care doctors and how they've been trained.

So we're going to talk about how the medical home really can help in the optimal care of young infants with hearing loss and how they can help support the EHDI program in general. So just as a way of background, one of the biggest programs that faces the EHDI programs, is, of course, loss of follow-up. While it is decreasing somewhat, it's still basically about 40%, and that really is not acceptable.

Additionally, we also have even babies that aren't lost to follow-up are what's called lost to treatment, and lost to treatment is essentially that in spite of -- and this is a study from Lynn Spivak at Long Island Jewish Hospital in New Hyde Park -- in spite of the 91% retest rate, only about 40% were fitted with hearing aids on time. And this was true, more true for babies that had Medicare and NICU babies and finally, according to C.D.C. information, only 60 to 70% of infants with hearing loss are enrolled by six months of age. So the feeling is all these areas can be improved by more active involvement of primary care doctors.

Now, some of the barriers to timely diagnosis and treatment that were laid out by Marcus Gaffney from the C.D.C., sometimes it's how the hospital presents their screening results and as was discussed many times that pediatricians don't really get the results. The documentation of the results and left out of reporting systems are cumbersome and easy to use. There are not that many pediatric audiologists in the country, and it's sometimes difficult to find audiologists who are experienced in taking care of infants and communicating with audiologists, both from the parents and the primary care physician are often a probability. And mobility, families move, sometimes they don't see the urgency, or it's not presented to them, a need for a rescreen is all that urgent, and sometimes, there are cost and transportation issues as well to get that follow-up, rescreen or diagnostic audiological evaluation.

Now, the medical home -- and some of these challenges are, I think, inherent in the results of the survey -- are that while congenital hearing loss is one of the most common congenital disorders, it's still a fairly low incidence as far as a practicing pediatrician goes. The other, as clearly pointed out by the survey, there's a lack of physician knowledge and we have

trouble communicating with each other, we speak different languages. Part of it is misconceptions that people have that were pointed out in the survey. Some see the success of Universal Born Hearing Screening, things are taken care of already, there's not that much for to us do, and I think that's why there's this lack of communication with the state EHDI programs. There's still difficulty in getting newborn results. I think the survey found that. I think most pediatricians, while they get information, they still have difficulty getting information. There's really poor integration with electronic medical records, so that seamless interplay of information and communication really just isn't there.

And then we have the whole aspect of retesting in the office, which we are going to talk about a little more, and really the lack of reporting these results to the state EHDI programs.

Additionally, family support, which is critical, is a challenge for many, many primary care doctors, and we know, and we're going to talk about how family support is probably the most important aspect of supporting infants with hearing loss.

Working with early intervention is a challenge for pediatricians. We often don't get information back. We often have difficulty getting the information that we have to them. And of course, the time constraints and financial constraints that everyone in every profession is faced with these days.

So Karl showed you the 1-3-6 chart from the American Academy of Pediatrics. I'm just going to go through this a little bit in terms of what the medical home role is. And we know before one month we want the babies to be rescreened if they didn't pass their tests, and this can be done in the hospital, can be done by an audiologist, and it being done more and more in the primary care setting. And we also know if you're going to test a baby in your office or even if you're going to retest a baby, it's important to know how they were tested in the hospital with an OAE or whether it should be an AABR.

Loss of follow-up documentation often occurs and often it's a lack of communication between the family and the hospital and the audiologist. Was the information conveyed to the family that it was urgent enough to take care of it but not alarming so that they're paralyzed with indecision. Is the primary care doctor being supportive enough, is there a protocol for how to take care of these things, does the office staff know what to do. And this goes without saying. If the child did not pass the newborn hearing screening, they must be retested and rescreened, and there are situations where they will advise the family, it's just fluid in the ear, don't worry about it, and that delays the retest.

So let's talk about office rescreening, and what I mean here is basically using the OAE in the primary care office to rescreen babies after they don't pass their hearing screen. Now, as was mentioned in the physician survey and also from some regional meetings out of New York State, about 25% of pediatricians are rescreening in the office, and if we could have a brief poll to see how people feel about this. If you could answer that, that would be very helpful in terms of what your feeling is about this.

Now, is rescreening helpful to parents? Does it make everyone's life easier? Clearly, if you can come into the office and get rescreened, it makes life easier than having to go to an audiologist and perhaps the audiologist isn't nearby. It would -- would parents feel more comfortable having the baby rescreened in the office, if it's a doctor they know or trust, but who does it and how are they trained and is the equipment calibrated? You know, so we know from this physician survey and from regional meetings that it's usually not the physician. It's medical assistants, and we know that mostly we're using OAEs and AABRs as Karl mentioned, somewhat difficult to use in the office.

And are doctors using it for the initial newborn screening? Clearly, no one recommends that and no one encourages that, but there was some evidence from both the physician survey and a New York State survey that some physicians are using it for screening if they can't get the initial results or if the baby was born in a birthing center where they didn't have newborn screening.

And 23% of the pediatricians that were surveyed in New York State said they were using it for an initial screen if it was necessary.

So we need to report to the state EHDI program, and unfortunately, at least in a study in New York State, only 12% of pediatricians were doing that, which is very consistent with the results from the physician survey.

Can we get this thing out of here? Okay. So the support of parents is critically important when they don't pass, that we use language that encourages follow-up, and most pediatricians are good at this, avoiding words like congenital which don't mean much to people in the field, to be sensitive to the different cultures and always retest the baby and really, we must assist in arranging this retest which means phone calls and perhaps a little bit of a personal touch or an office manager or someone in your office that can make sure that they follow up on this critically important developmental emergency of a baby who did not pass the newborn hearing screen.

So now back to 1-3-6, before three months we want to get that pediatric audiological, reported to the EHDI program, referred the baby to early intervention as well as family support, how to refer the baby to those subspecialists that were discussed earlier, and if the family would like to have hearing aids, then by three months, and process should already have been started and along the road.

Now, but, you know, as far as pediatricians go and as far as people who work with pediatricians -- and we're very involved in this, so we see a number of babies that have hearing loss and we work with their families, but 90% of children who are born Deaf or lose their hearing are born to hearing parents who essentially have no idea of what this is all about. And conversely, 90% of the children of Deaf parents are hearing. So that both the parents and the doctors, this is a relatively uncommon event. And when we're talking to parents who really have never met a Deaf person in their life and now they have a baby who is hard of hearing, it can be very confusing and difficult for them and for people who communicate with them.

Now, this is information that comes from Hands and Voices, and the most important predictor of success is meaningful and effectively family involvement. I don't think I need to explain this to the people on this webinar, but less than 50%, less than 50% of parents receive the support that they needed. And that's very sad. And what's also very interesting is that parents are more likely to get support when they were encouraged to do so. And that's really a role for the primary care doctor, to encourage the support and to connect the families with the Hands and Voices chapter in their state at a very, very early stage in this, because direct parent-to-parent support is really one of the strongest measures of people support and while face-to-face interactions with professionals is also important, it's the Hands and Voices support that can make a significant difference.

And this is a study that a lot of us are familiar with, the study that shows that early intervention, early treatment is important. But here is a study that shows the language scores by age of enrollment in early intervention. So clearly, the earlier a child is involved in early intervention, then the better their language scores. And this is from a study by Pat Moeller that was in pediatrics a long time ago in 2000. But here is a really interesting aspect of it. It looks at both age of enrollment and early intervention as well as a measure of parent involvement in the child's care. And you can see that the earlier the involvement and the higher the involvement of the parent, the scores and language scores were essentially normal.

So it is critical for pediatricians to not only support families but to get the children involved in early intervention as soon as possible.

Okay. So now before six months, we want early intervention services in place, we want to start working on the etiology and the associated problems and that refers all we talked about, and we should have follow-up audiological and the hearing aids being fitted.

Now, why are these subspecialty evaluations so important? For a number of reasons. One-third of children with a hearing loss have another major disability, and clearly, the earlier we identify this, the better off the child's outcome and the better off we can in terms of treatment and family education and intervention.

Now, genetics is critically important, because genetic counseling is important in terms of families understanding why their children has a hearing loss, whether other families may be affected as far as other children, and there are a lot of syndromes that go along with it that are important to note, importantly, Usher Syndrome where you can have seeing problems as well as other issues.

As far as eye examination goes, it's clearly important to optimize vision, but there are co-existing vision issues in some children with hearing loss that can help to assess the etiology and it can help you make a diagnosis in terms of specifically CMV and other infections.

Referral is important, but not to make the first referral to an ENT. The first should be for a rescreen and the early screening, and then the ENT is important to discuss the stats of the cochlear, the cochlear nerve. Often, temporal bone imaging is done, and it can be abnormal in a number of cases and that can help define the etiology and identify hearing losses and conditions that might encourage different kinds of management, for example, children where sports with a large vestibular aqueduct where it can make it worse. And parents should know about these as soon as possible.

So what about the risk factors? Why are they important and for the practicing pediatrician? Because 40% of hearing loss occurs after the newborn period, so that it's really up to the pediatrician to help identify this, because we as pediatricians see these children many, many times in these first few years. So it's particularly distressing from the physician survey that many pediatricians were not aware of all these risk factors.

And here's a list of them, which most of you know. NICU graduates, family history of hearing loss, CMV particularly is very important and probably the most common cause of a late-onset hearing loss. Craniofacial abnormalities, child abuse,

meningitis, and don't forget that children on chemotherapy have a much higher incidence of hearing loss.

For pediatricians, the newborn period is the beginning, but we really do ongoing care and monitoring of hearing, speech, and development issues. We try to aggressively treat middle ear disease. We do routine hearing and vision screening. You know that Bright Futures doesn't recommend getting those until the age of four, which we all feel this is extremely late, and with OAEs, they're screening them at one, two, and three years of age. Any of us who have OAEs and use it to screen, I'm sure, have picked up children with late-onset hearing loss. I know I have. Kids who maybe come from another doctor who had been diagnosed with speech and language impairment and then you do the OAE and you find out that they have a hearing loss, even though they passed the newborn hearing screen.

We know that only 20% of primary care pediatricians in the country screen for general development and autism. And that's a major concern. The recommendations from the JCIH, 24 to 30 months. I think most of us would refer before that, especially now with the technology to diagnose hearing loss much earlier.

Now, here is -- these are just some reprints of the AAP, EHDI lost to follow-up recommendation. There's a survey, if you could put that up, of the eight physicians on the call and for nonphysicians, if you have any knowledge of these guidelines they put out last summer, there is newborn hearing screening, lost to documented follow-up is the first one, the other one is an algorithm which -- an algorithm form, a checklist form. These are available, if you go to [www.AAP.org](http://www.AAP.org), if you go to the search, you have to go in lost to follow-up. It doesn't come up if you put in EHDI, so put in lost to follow-up. These were created by an EHDI task force, the AAP-EHDI task force have been streamlined. It has been really the number of people has been reduced and is consisting primarily of pediatricians at this time.

This was given out at the -- in the AAP, news publication and is available on the website. So I'm going to just briefly summarize what this says, and if you're interested, you can look at it. I think this is important information for not only pediatricians but for people who are trying to work with pediatricians to know what the expectation is for them in the medical home to help families with young infants with hearing loss.

So the first part is to obtain document and to discuss all screening test results and factors by one month. We are trying to get that information from the hospital rather than from a parent, to take some of the burden off the parents to report that information. It's not appropriate, really, for parents to



do. There has to be better communication between the hospital and the primary care doctor.

It is really the role of the medical home to coordinate care, and that is either screen, rescreen, or arrange a screen by one month of age. And if the medical home has to take the lead in this and has to assist parents with rescreening. And that doesn't mean to take a phone number and have them make a phone call. It means to have them actively involved to get this done. We feel it is reasonable for the medical home to confirm results with the EHDI program within 48 hours, meaning if the child did not pass the newborn hearing screen, which is not all that common occurrence, it is important for the pediatrician to confirm whether the child did not pass the rescreen or whether they did pass the rescreen.

It's important if the second screen was not passed for the pediatrician to take the lead in getting that audiological evaluation and notify the state EHDI program and to ensure at this point that the family is referred to a local early intervention program, and that doesn't just mean sending the people, but to follow up to make sure that the family signs a release to get that information and all that information is kept in the medical chart so it's available to the parents and anyone else who wants to know what's going on.

One of the recommendations is perhaps to have a dedicated staff person in the office that can develop a relationship with the state EHDI program and see how it works, coordinate the efforts of the families and be that point person to get all screening results. Doesn't have to be their only job, but it seems to work better if there's one person who knows what's going on with that.

Again, just to reiterate, you need to provide education and support to families. That means to discuss milestones with them, to discuss all the results and in a way that's understandable and confirm that all the appointments were made and even to arrange transportation and social service report when necessary and to do this in a culturally confident and health literate way and there are a number of organizations in our states -- Hands and Voices, NCHAM -- who can provide this information to pediatricians.

Now, the rescreening guidelines, I'm not going to go into. We've talked about it a lot. Let me just say that except in rare circumstances, the medical home should not conduct the newborn hearing screening for a number of reasons. In some circumstances an AABR may be warranted to rule out auditory neuropathy, although auditory neuropathy in healthy newborns is very rare. And information presented at the 2013 EHDI Conference had it about 1 in 600,000 healthy newborns, so that

screening with OAE in the pediatric office, particularly if the child doesn't pass, is a helpful thing to move the child along to get a diagnostic audiological diagnostic information, but you must report it to the state, and NICU graduated -- and I can't stress this enough -- should not be retested with an OAE in the office. They should have been tested with an AABR in the hospital. There is a much, much higher incidence of auditory neuropathy and it's not appropriate to retest a NICU graduate with an OAE in the primary care office.

So why do people want to interface with pediatricians and why is it important to get pediatricians on board? Because the C.D.C. data shows that pediatricians are the number one top trusted source, even more than morning TV shows or magazine articles. And so people listen to their pediatricians. They trust their pediatricians. And so it's important that we are all on board in terms of doing what's best for these families and working with our state EHDI programs.

So how do you reach the primary care doctor? And this is some information from the C.D.C. and from a study that we did hear in New York and from Texas, and I know that in Connecticut as well, this seem to be the experience there. So the first thing is decide who you want to reach and who is reachable. Not everyone is going to change their practices, and we don't have unlimited resources. We know that face-to-face visits are probably the most successful way. It's the pharmaceutical rep, the drug rep model. You bring some food. You bring some gifts. You give a brief and focused presentation, interface with the office manager, who really runs most pediatricians' offices and try to get a champion on board who is enthusiastic about it.

Website with online and printable materials are important. Just-in-time information that can be put on the desktop is important. Journal articles, probably less effective. Mobile application for the younger doctor, yes, it must be easy to use, and the least effective, unfortunately, are conference and phone calls and grand rounds, and unfortunately, clinical guidelines. The bottom line here is that face to face personal connections seems to be the way to go in terms of getting pediatricians and primary care doctors to change their behaviors.

So can the medical home reduce the lost to follow-up? It's hard to know, but we'll refer to Yogi Berra. It's tough to make predictions, especially about the future. Most people on this call have been trying, and the hope is by involving the pediatricians and the primary care doctors, we will be able to help reduce lost to follow-up and improve the lives of our families with young infants that have hearing loss. So that's -- thank you very much.

>> DIANE BEHL: Thank you so much. Those were excellent strategies in particular in terms of reaching physicians. To reiterate what Jack said about where to find those resources, such as the guidelines for lost to follow-up, there's two places you can go to, [infanthearing.org](http://infanthearing.org) on our medical home link and also on the AAP, the link is there as well to find the tools that way. You can also revisit our NCHAM website for a recording of this.

At this point I would like to open it up to you all. So please offer up some questions or comments, and you can do that by having them in the chat box here to your left where it says Q&A. All right. I see some coming in. Jane is wondering if we can get the PowerPoint. Yes, Jane, we will have this on our website for future viewing. I'm hoping that answers your question.

>> KARL WHITE: And Diane, the question whether they can use these slides in their own, speaking for the NCHAM, you're more than welcome to use those, if you will reference that it came from the NCHAM study so if people want to come back and get more detailed information, they can, but I can't speak for Jack, but for the slides from NCHAM, you're certainly welcome to use those.

>> JACK LEVINE: Sure, it's okay to use the slides. It's good if you give credit to where they came from.

>> KARL WHITE: Were all of those from the survey discussed today? You can get a copy of the survey. I think we discussed it. We didn't discuss the cross tab set analyses, but if you e-mail me at NCHAM, I can send you a copy of the actual survey that was used.

>> DIANE BEHL: Thanks, Karl. And going through here, one question is, it's in regard to, I think, how about in-office screenings are being conducted. There was reference to use of questionnaires, and the question is, which one is best to use of the questionnaires.

>> KARL WHITE: So let me give you my opinion. This is Karl. I think using a questionnaire in a physician's office as a way of screening would be the least desirable technique. And I'm not familiar with one that is used more than others in terms of a standardized questionnaire. Certainly if parents have concerns about their children's hearing or their language development, then the very best thing to do would be to arrange for an evaluation by a pediatric audiologist. But there's quite a bit of data showing if you're trying to detect hearing loss from either maternal questionnaires or teacher questionnaires that the sensitivity and specificity of those instruments is just horrible. So my recommendation would be to not use questionnaires.

>> JACK LEVINE: This is Jack. I'm not sure, but I'm not sure, but developmental screening is done usually nine, 18, and 24 or 30 months. Those are the parent questionnaires, the ages and stages and the SWIC and PGIS (phonetic) are used, and clearly, if anyone had language concerns on those developmental questionnaires, you would order an audiological, but that's a little bit late, by nine months, already.

>> KARL WHITE: Yeah, my comments were if you're focusing on hearing. I'm not saying the ages and stages are not appropriate to use.

>> JACK LEVINE: I don't know of any for hearing that are valid. Do you want me to answer -- I can answer this question about the upcoming changes to conduct OAE screening and well child checks earlier and more frequently.

>> DIANE BEHL: Perfect.

>> JACK LEVINE: That has been discussed quite frequently. The latest report that came out on kind of ambulatory management of hearing and language delay kind of hints at it, but it's a little bit difficult for them to make this recommendation because it would really require more pediatricians to get an OAE or -- and that's something that takes a really long time for most of these organizations to come through. So while I believe there's a lot of discussion of it, I'm not aware of any immediate change in the recommendations on using a physiological screen in the office before the age of four.

>> KARL WHITE: So this is Karl. There's a question about doing early childhood screening referencing the work that has been done on screening in head start and early Head Start programs and how effective that has been in identifying children with hearing loss, but pointing out that so few children, relatively speaking, who attend Head Start, less than a million, roughly 10% of the population. Couldn't we do similar things in physician offices and are there studies that have looked at that? I think the answer is yes, as long as people are well trained and have appropriate support. There are a few studies. One is -- was by Parul Bhatia in southern California where they did screening in community health clinics and another by William Lennon and Terry Faust here at NCHAM where they also did community and health clinics. Both identified it as an effective way to identify children with hearing loss. There may be other studies as well that I'm not familiar with. I think the fact that you can do screening of young children in the healthcare setting and effectively identify hearing loss is very clear. What we need to make sure, based on the survey results, is that if screening is being done in those physician offices, and needs to be done well. For it to happen and be done well, many people need appropriate training and support.

>> DIANE BEHL: Great. Thanks. There's a question here also asking about the need for better reimbursement for doing OAEs in the office. Jack, I wonder if you want to comment about that, any strategies for increasing reimbursement.

>> JACK LEVINE: So it's -- it is a bit of a battle. I think in certain cases, you can get reimbursed, for example, in a child with developmental disabilities, in a child who perhaps has some kind of, you know, congenital abnormality. I think the question is probably about routine screening with an OAE, and some insurance companies will pay for it. They will pay like, say, between one and three years of age, and after that, they say, you should use an audio sweep. Medicaid in some states will not pay for it. I was on a call with AAP and the insurance companies, they're very firm in not doing it. I think if you've kind of made it a -- an advocacy project or something that you wanted to work on, I think we could probably get it done because it makes so much sense. But it's really up to the individual insurance company, and they're not happy to -- to just pay for things when the recommendation from the AAP is that you don't have to screen until four years of age.

>> DIANE BEHL: All right.

>> KARL WHITE: So there's a question here, or a comment, that there is a question there called Little Ears, that is produced by the Med El company that is focused on identifying hearing loss, and the person said there was some reliability and validity studies done, just as an FYI. Whoever made those comments, please send me those references. I would be very interested in seeing them.

>> DIANE BEHL: Good. There's a question here, do you have any suggestions for actions, EHDI programs can take when medical home providers do not comply with recommendations to refer for an audiology evaluation after the infant does not pass screening in their office. Karl or Jack, any recommendations there?

>> KARL WHITE: This is Karl, and then, Jack, you can add comments. I think Jack did a great job of summarizing what worked best and least best, and what works best was the face visits where they have that individualized education. You can't force people to do it, but I think the biggest impediment is the education, and we've learned by sad experience, doing these kind of webinars has little effect. It's time intensive and personnel intensive to do those face-to-face visits, but that's what has the biggest impact. And hand in hand with that is having the parents ask for information from the physicians and reporting back when good things happen as a result of being referred to an audiologist so that physicians know that there are some good things resulting from that.

Any other suggestions, Jack?

>> JACK LEVINE: You know, the thing, the analogy is the metabolic screen, the blood spot. If you have a baby who -- has like an abnormality on, it you get an official letter from the state Department of Health. You get a fax that says, if you don't respond to this within, like, two weeks, we're going to -- you're going to be -- the baby is going to have serious problems and for some reason, pediatricians respond to that immediately. I don't know exactly why they often don't respond to the -- not passing a newborn hearing screen, but I don't know what you can do other than, like, as Karl said, to connect with them personally. But I would really talk to the office manager. That's the person who really can make changes in an office, because a pediatrician may talk to you on the phone and just let the conversation go. But an office manager would be the one to make policy changes in the office or encourage the pediatrician to do it. It's important for the office to have that front person and the EHDI state coordinator to be in contact with that person. That is the person that can get things done in an office.

>> KARL WHITE: So there's a very specific question here. I have two kids with prolonged QT syndrome who have sensorineural hearing loss. Any thoughts on making EKG part of the routine screening process? Jack, what are your thoughts about that?

>> JACK LEVINE: It certainly is simple enough -- well, it's not that simple in an infant. But certainly it makes a lot of sense. I'm not sure, maybe if people would refer to genetics more frequently, they would be getting the EKG done. I'm curious as to how the EKG -- at what age it was actually done and who recommended getting it. But maybe if people refer to genetics more often, they would get more EKGs done.

>> KARL WHITE: Yeah, this is Karl. It seems to me that to do the EKG as a routine part of the office visits would be quite expensive. But the genetic evaluation -- I mean, and those aren't free either, but the prices are coming down, at least, if you're doing the genetic evaluation for just the most common mutations that lead to hearing loss. And insurance has been good about paying for those genetic evaluations. That's the part where I think we would make the most progress the most rapidly, if we got many, many more families being referred for the E -- for the genetic evaluations.

>> DIANE BEHL: There are several questions related to, I think, the nuances with the guidelines. The AAP says that anyone with a JCIH risk factor has to go to audiology by 24 months. Does that mean the physicians don't do the OAE at all in the clinic?

>> JACK LEVINE: This is Jack. I'm just saying from my own personal experience -- this hearing loss isn't just in a vacuum,

especially if the baby passes a newborn hearing screen and has risk factors. It's important to identify language development also. If you find that the language isn't developing normally, then you would refer much earlier than two years, even if the baby was, you know, not making as many sounds or responding to sound. So that's one aspect. The other aspect, in my own personal experience, I would think if the child had significant risk factors, most pediatricians would refer them earlier than 24 months. That's my own personal. And JCIH may change the recommendations, from what I understand, anyway.

>> DIANE BEHL: Great. There's some other questions here in regard to if we do WCC screening in healthy toddlers, can we do an OAE in the ex-NICU graduate, assuming they pass the AABR at the end of the NICU stay? Any recommendations with later screening?

>> JACK LEVINE: I would say the same answer. You have to follow the child's development. If they passed the newborn screening and they're developing really well and their language is coming along nicely and there's no developmental concerns, you know, I'm not sure I see a huge problem with an OAE.

If there's any concerns, though, and the child is not speaking properly, or has language delay, I would not do an OAE in the office. I would get an audiological evaluation. That's the role of the pediatrician, particularly outside the newborn period with EHDI program with hearing losses, we see the child as whole with the language development and other aspect of the development which is integral to language development. If there's a delay in language, we would certainly be getting a hearing test sooner than later, and if it's a NICU graduate, I would send for an evaluation rather than OAE in the office.

>> KARL WHITE: So a couple of quick responses to questions here. When will the recorded presentation be available to share with our medical homes? They're typically up on the website in a week. You can find them there.

How do physicians learn about early intervention programs in their area? If you go to [infanthearing.org](http://infanthearing.org) and click on early intervention, then there's a list of all the Part C coordinators in every state, so each state has program that is specifically responsible for making sure that early intervention services are available for all children with disabilities and you could contact that office and get a list of programs that are providing services to children with hearing loss.

Many parents are reassured that a referral on the newborn hearing screening is due to fluid in the ears, as you mentioned. Do you think that giving this reassurance be discontinued? I think it should absolutely be discontinued. What we should do when that child fails that newborn hearing screen, not to alarm

parents, but to impress them with the urgency of following up. We know that only 3 children per thousand have hearing loss, but once they've failed that initial screening in the hospital, it goes to 3 children per 100 or 3 children per 50, depending what screening was used. So the risk is much, much higher and it would be very good to impress that upon the parents that this is important to follow up.

There's also a comment made about our recommendation to do face-to-face visits with physician office, and the comment was, one visit is not enough. During the visit you get their attention but you need to go back, help them walk through the process and see how it works and sometimes do a third visit, and it really is time intensive for that to happen.

>> DIANE BEHL: Karl, this is Diane. If I could add one thing too, another valuable resource for physicians is a tool that NCHAM has on their website under the "family support" link which is a just-in-time, very short handout that lists the critical programs and services out there to link families to if they have any concerns about their child's hearing, and that handout will tell you where to go for state-specific information, if that is available in other languages, et cetera.

>> KARL WHITE: Great. There's a question here, why is it not helpful to ask parents about their baby's newborn hearing screening results? It seems this would be the best way to obtain this information if there's difficulty with sending the results from the PCP from the hospital. We've actually collected a fair amount of data on looking at how accurately parents report the results of the newborn hearing screening. And the answer is, not very accurately. And so when the parent comes into the PCP's office, they frequently give incorrect information about whether their baby was screened and what the results were. Probably a function of how many other things are happening at the time that baby is born and how much information is given to parents. And so it certainly is worth -- I mean, it's always important to communicate with parents, but I think it's -- not a good idea to rely totally on the accuracy of what they're reporting.

>> JACK LEVINE: Yeah, I'd like to just -- I think that's really true, and I'm happy to hear that you actually have information. I think it depends on like the people -- the people in your practice. I know for me, I've had people who confuse the fact that they signed for hepatitis B vaccine with the fact that the child got a hearing test. And once that happened, I really try very hard not to just rely, just rely on what the parent says.

And the flip side of that, if we stop relying on what the parent says, we have to work closely with the hospital to make



sure they make every effort to get us those results. One of the questions here, what happens when you don't know who the primary care physician is, and that's an important point and one that is difficult to solve. In other words, the parents don't know who the primary care doctor is. They might have a Medicaid managed care where they're going to get assigned a PCP. They often don't get assigned a PCP or they go to a healthcare center and they don't know which one or it might be in a neighboring state and it's up to the hospital to get as much information from the parents and the caregiver to follow up with that. That's a problem that's very difficult to find a solution for.

>> KARL WHITE: Another question here, what about when a parent has taken her child to several pediatricians with concerns about hearing loss, the pediatrician says the child is fine and refuses to do hearing screenings. That can certainly happen, and I think you need to find a pediatric audiologist who would do an assessment, and oftentimes for insurance purposes, that may need to run through the physician's office.

The EHDI chat -- not the EHDI chat, the EDHI-PALS program certainly gives lists of practices who are experienced and who have the ability to do pediatric assessments, but I think the worse thing the parent can do if they have concerned about their child's hearing is not to do anything, and that's where the EHDI program can be an important support, too, and finding people who can do the assessments.

>> JACK LEVINE: There's a question here, can you expand on the appropriate time to bring on the ENT or otolaryngologist, and I think when the baby doesn't pass the newborn hearing screen, they refer to an ENT rather than an audiologist, and some ENT doctors are capable of testing newborns, but most probably aren't unless they're at large medical centers. So really, I think, anyway, my interpretation is that the ENT evaluation is that subspecialty evaluation to see if there's an etiology or some additional information, but the first set of referrals really needs to be for the rescreen and for the diagnostic audiological which really -- an audiologist should probably be doing.

>> KARL WHITE: Here's a question, we do OAE and if fail, automatically get tympanogram. Is that what others are doing or the physicians or are there pediatricians who have ABCs in the office?

>> JACK LEVINE: Is that conductive hearing loss or congenital hearing loss?

>> KARL WHITE: Yeah, to screen for conductive hearing loss. Yeah. Thanks. Certainly there's nothing wrong with that. It's good practice. On the other hand, if they fail the OAE, probably the best person to sort all of that out at that point

would be an audiologist. So if there are people in your physician's office who are very good at doing both OAEs and tympanograms, that would help to rule out conductive hearing loss, but I think my recommendation would be, if they fail at OAE in the physician's office, they be referred to an audiologist. Jack, do you have thoughts on that?

>> JACK LEVINE: If they fail an OAE in the office and they have fluid?

>> KARL WHITE: Yeah. If they fail the OAE in the office, should the next step be to recommend that the physician do tympanograms or at that point should you just refer them to an audiologist? Certainly if they do a tympanogram and they have fluid, it's less clear, but it could be mixed where they have fluid but still a sensory neural hearing loss and I would rather see an experienced audiologist sorting that out.

>> JACK LEVINE: I think that would be optimal, especially if the child had other concerns or language delay I would recommend it. If the child had a cold or ear infection, but I would have them come back. I wouldn't keep a child who keeps failing an OAE without referring them for audiological. Many kids have gotten into trouble on that. I would agree, basically.

>> KARL WHITE: Jack, here's one I don't know the answer to. How long do you need to be exposed to ototoxic medications to require rescreening, such as diuretics or Gentamicin?

>> JACK LEVINE: I don't know the answer to that, but there are plenty of people on the call that do know the answer to that.

>> KARL WHITE: We only scheduled this for an hour and a half. There are lots more questions. What we will do is those questions that we haven't been able to get to, we will post answers on the website along with the recording of this presentation. So I know all of you are very busy people, and I notice from the sign on list that we're beginning to lose people now who probably have other obligations, so probably time to draw this to a close, but we will answer the other questions that have been posted that we haven't gotten to. Diane or Jack, anything else?

>> DIANE BEHL: I have one more request for participants, and that's to give us some feedback on the quality of this webinar today, and so we do have one more quick poll that we're going to put up. If you could please give us some of your candid feedback on that, that would be wonderful.

>> JACK LEVINE: I just want to thank everyone for being on this and all the great interest and work that everyone does, and I would like to thank NCHAM for including me in this and being able to facilitate the communication between pediatricians and

primary care providers and the EHDI program. For me, that's where the future is and what the best solutions are.

>> DIANE BEHL: And Jack, thank you for just really, you know, being the inspiration for a lot of the work that we're doing with the medical homes and really giving us important reality checks of what physicians are experiencing. So thank you. And thanks to all the participants and please look for a notification to be coming your way about where to get the recordings and answers to your other questions today. Thank you, and have a good remainder of the day.

(End of session at 3:29 p.m.)