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SPEAKER:

Hello everyone. We welcome you. It is good to see you joining. We will be starting here in a few minutes at noon, Mountain standard Time.

Mike, I think we can go ahead and get started. Welcome everyone, Tuesday's webinar. I will (indiscernible) in a moment.-- Today's webinar.

Please note, today's presentation is being recorded as you just heard. If you require close captioning, click the life transcript button at the bottom of your screen, and select show subtitle.

I will go ahead and enable the club according OK, -- cloud recording.

URSULA FINDLEN:

Thank you everyone for joining us either this afternoon or this morning, depending on what time zone you are in. I am excited to see so many people from across the country. I am here with a great colleague and mentor, Doctor Lisa Hunter, to present systematic review of multidisciplinary team hours completed recently learning from our past for a better future.

We do want to thank NCHAM for his opportunity to share his work with you.

I do want to recognize the rest of our team. As I mentioned we are a multidisciplinary team from multiple distant-- different facilities working together. We are trying to look at all factors that can either help or hinder families going through the 136 process for early intervention and EB HIV in general.-- EHDI.

Doctor Hunter will introduce herself when she is ready to begin her part of the presentation, which is later in the hour.

My name is Ursula Findlen. I am the director of research at Nationwide Children's Hospital in Columbus Ohio, also an assistant professor of clinical at the Ohio State University Medical Center, within the Department of oncology head and neck surgery.

I have a special interest in EHDI, in my research interest include trying to facilitate early identification and intervention for children who have hearing loss, so they can meet their best outcomes.

So today, we are going to do is identify the barriers to timely EHDI, as well as discuss successful facilitators of EHDI that we found throughout the literature.

There also want to discuss a little bit about implementing quality and improvement measures in different programs to facilitate Early Hearing Detection and Intervention in the United States.

Most of us on this webinar are aware that the incidence of congenital hearing loss is 123 per 1000 infants, and we also know that--1 to 3... It can have significant about mental locations related to speech inlet with development, cognition, academic achievement, vocational opportunities, and overall quality of life.

We know there is a very specific critical window for us to diagnose and interview and provide management and early intervention for these children within the first six months of life, because of the data shows that as long as that timeline is set to, children can't maximize their outcomes regardless of what pathway they choose for communication. Whether it be oral and listening and spoken language, or total communication, or manual communication via ASL.

We know that since the inception of universal newborn screening programs in the United States, that screening rates in hospitals have grown very high, and have stayed consistently high. The success rate for both diagnostic follow-up early intervention group and have really lagged behind.

If we look at the most recent CBC available data from 2019, but we can see is that 96% of all children born in that year received their newborn hearing screening, and of the children that were screen, 97% of them got them by one month of age.

When we look at the diagnosis in early intervention portions of EHDI, what we see is that actually less than half of the infants who did not pass the screening were diagnosed, or got a diagnostic by three months of age, and of the children who ended up having diagnosed hearing loss, about 79% of those were diagnosed by three months of age.

Lastly, when it comes to early intervention enrollments, infants with hearing loss that were identified through the process, I'll be 44% of those children were enrolled in early intervention services, of the infants receiving early intervention services, 72% of them received them by six months.

What we see here is we are at a place in our program, where we are doing a really good job screening identifying risk for hearing loss, but we are really lagging behind in the diagnosis and intervention phases where it is critical to understand if these children have developmentally significant hearing loss, what we can do to help them reach their best potential.

To that end, group got together and we wanted to do a systematic literature pertaining to the entire EHDI process, to identify both factors that serve as barriers to families moving through the process, as well as identifying facilitators for timely benchmarks.

What we did, is be registered this with prosperity, and did a systematic search of multiple databases back in May and August 2021. Use multiple different types of mesh terms specifically hearing loss, diagnosis, early medical intervention, follow-up, early detection and intervention. In order to identify literature that might include articles that address barriers of facilitators.

We then used a COVID and systematic review software to move through three stages of review. In the

first stage, two independent reviewers from a team looked at titles and abstracts, and wanted to make sure that these articles were actually relevant to what we were looking for. If there was any conflicts of managing reviewer review these conflicts.

In the second stage of the review, those articles that remained were independently reviewed by two reviewers, and the entire article was left there to make sure that it really did meet the standards for our inclusion and exclusion criteria, or articles that provide information about barriers and facilitators.

Again, disagreements resolved by 1/3 member of the research team, or by consensus.

Lastly, when we got onto the number of articles we thought representative of the literature we wanted to review, we engaged in data extraction. In that process, two independent reviewers from our team looked at predetermined variables, and extracted the design of the study, the population characteristics, some of the outcome measures, as well as any barriers or facilitators provided.

We also included a quality review using the critical appraisal skills program for the CAS. We looked at both the data extractions from the first two, and result any conflicts between the two reviewers.

These are our inclusion and exclusion criteria. What you can see from this is that we really wanted to pinpoint literatures that has been published since 1990, to capture what we have learned since the inception of that universal hearing screening program, that started popping up in the mid-90s in the United States.

We focused on the birth to three population, and focus on English-language peer-reviewed articles.

Lastly, I wanted to point out that we did specifically try, or we did actually look at only US articles, because across the world, there are many different programs and different factors that can contribute to other EHDl occurs in a timely fashion. Some of those factors include developing countries they be just starting out with screening protocols, versus well-developed program like we might have been one of our states, versus more developed countries who probably have had these protocols for a long time, but have a different insurance scheme. That also can impact the results that they get.

Our review was very specific to the US.

During our categorization, we took all of the extracted data, and we went to look at these articles on two different dimensions. First, we looked at it and if these articles are addressed a specific part of the journey, or the entire journey. So we categorize articles based on whether they adjust screening, diagnosis, management, and here we really focus on management being provision of unification or a specific type of device to manage the diagnostic hearing loss, and that is in contrast to early intervention where it is the implementation of either a part C early intervention program, or speech pathology program for children.

Lastly, the articles that will be addressing the entire journey.

Then they also look at this from the factor type. What that means, is me look at all the barriers of facilitators, and realized that there are some factors that are specific to individuals or families, and there are other factors that are specific to system-level factors, meaning it is a product of the state specific program, or a hospital program.

We characterize these articles in terms of what part of the EHDl journey they adjust, as well as what part of the factors they addressed.

For the rest of this webinar, we are going to go through both barriers and facilitators of EHDl, first over the whole journey, and some factories actually were they are only specific to specific parts of the EHDl journey.

Before we get to all the good information, we actually wanted to do a pull to figure out what you are all experiencing in your programs as barriers that might hinder families moving through the process. You can actually join this old--poll that he will cook with your smart phone. You can text my name and that number. It is Ursula Findlen.

Want to join, it will not be activated yet. It will be activated when I go to the next slide. If you could enter, text some of the factors that might hinder your families move through the process.

If technology is on my side, we should see a word cloud popping up here in a second as people enter their responses. Hopefully people had a chance to enter the pole.--poll.

There we go. Information, share information, family biases. Handoffs, providers, family messaging, distance, yes. Language, cost, Yep.

As you can see as the word cloud is coming through, the words that are getting bigger means that there is a local or people responding there.

Providers, language, education, communication, distance, these are all things that we found within our meal. On one hand, it is good to know the experiencing, but we also don't want to experience those things.

We are going to move on now.

The results of our systematic review, the original article searches came up with 672 articles. 108 of which were duplicates. That left 564 for us to screen, and after reviewing the title and abstract of a number of them, we came up with 169 that we need to review for fulltext.

Of those, 107 were excluded. They were excluded for a number of different reasons, but most often they were excluded because they didn't dress very specifically. Ultimately, we were left with 62 studies to include in the review.

In terms of the categorization analysis, one can see here again, we categorized these articles by what

they are addressed across the journey, laws individual and system-level factors.

This is the number of articles that addressed each of these things. You will see that it doesn't add up to 62, and that is because a number of articles addressed many things.

Interestingly enough, we have the most number of articles addressing the diagnostic phase of the EHDI program. I bet you if we had included articles from before 1990, the numbers would have switched in screening would have been the winter.

You know, this just goes to show how much work has been done in each of these EHDI steps, and how much we have to learn from the literature that we have.

Before diving into the specific barriers, I wanted to make a comment about social determinants of health. We all know by this point that we have social determinants of health as a very specific factor to adequate access to quality healthcare.

Healthy people 2030 Debbie up social determinants of health in at least five domains including education, Access, equality, health care access and quality, neighborhood environment, social and community context, stability.

So, what I am going to do is as we discussed these barriers and facilitators, I am going to highlight where these social determinants of health pop-up, because it is a running theme especially when it comes to barriers.

Onto the barriers. We are going to start with the entire EHDI journey.

Lenore Holt colleagues posted an article in D12 of the subset of children they had in their studies, and they found that only 32% of infants that did not pass the newborn hearing screening actually met the 136 benchmarks.

We can see this every year when the CDC data is released, even though the denominator changes at each point going from all births to only children who fail the newborn hearing screening, to only children who have a diagnosed hearing loss.

We can see that there is a very small subset of children that are actually meeting that 136 the entire timeline. The factors that we are going to discuss now, some of them impact the entire thing holistically and some only specifically impact one part of the journey.

In terms of social determinants of health that impact the entire journey, the literature shows us that families with limited income really struggled to complete the EDHI process.

Those of Hispanic or native designed experience more barriers to completing EDHI. There is positive maternal smoking during pregnancy as well as family response abilities which will come up often during the stock. Families who have more children, child care or work or school responsibilities often

struggle trying to make their appointments because they have a lot of other responsibilities to address.

When it comes to quality healthcare and access literature shows us the families that have public insurance often struggled to complete the process. There is an effective access to her distance from healthcare facilities.

This is highly related to neighborhood and built environment in the sense that morality can cause a built-in access problem. The more rural that we get, the further away that we are from healthcare centers that offer specialty services.

There are a number of articles that address that issue. Transportation is also a factor but it can be found in both rural and urban areas. Just because the family lives in a more urban area that may have transportation, it doesn't mean that they own transportation themselves to get to appointments.

We always look at maternal factors when it comes to healthcare and how things are related. Maternal factors are not really just about the mother. It is really about the proxy for the family.

When we look at the literature, it showed us that when there is a lower maternal education level, they are less likely to process – of the process of EHDI finalize, and it is more likely for those benchmarks to be protected beyond the 136.

Lower maternal age is associated with lower completion rates, as well as unmarried mother status at the time of birth. There is a couple of articles that really specifically address maternal depression. It showed that mothers who endorse more post part of -- partum depression symptoms usually have delayed or lack of follow-up for EHDI benchmarks.

Medical factors can also be an issue for finalizing the process. Children with multiple medical needs that have a NICU stay often don't get the newborn hearing screening in a timely manner. Corrective age is better at meeting the 136 but for the most part some of these children are presenting with medical needs that need to be addressed before hearing is.

These children often have a protracted EHDI timeline and the exception that we found in the literature is really related to inpatient audiology programs. There were a couple of articles that specifically showed that inpatient audiology programs at major medical centers actually facilitate EHDI in this population.

For those of us who do diagnostic testing, we all know that transient middle ear issues can wreak havoc on the diagnostic process. Middle ear fluid or conductive hearing loss can very much complicate diagnosis.

The follow-up that needs to occur as well as the management. Family knowledge has also been studied. We have really shown in the literature that knowledge of results and resources, when that is not provided, when the families don't have the knowledge that they need to be successful, it causes

significant confusion about the process and throughout the literature, it has been often related to language barriers and cultural competence of the programs themselves being able to provide the family for knowledge that they need in the way that they needed.

Specific with family knowledge, families who do not know the screening or diagnostic results or any recommendations are obviously less likely to follow up. They can't follow up on a recommendation that they are not aware of.

Even if families know that they have to follow-up, the literature shows us that families often don't know where to follow up. These information gaps are really causing families not to have the tools that they need to be successful in the program.

There was another article that looks specifically at the knowledge base of families in terms of the impact that hearing loss has on development. They found that families who have less knowledge about the developmental impact of hearing loss are less likely to follow up.

Provider knowledge has also been really widely studied and it is hard to believe that in 2022, we still have physician dismissal. Following up from a newborn hearing screening. Families continue to anecdotally report this and certainly in the literature we have found that this was often an issue with families getting timely follow-up. In one article, they searched the PCP electronic medical records to see if documentation of screening results were there. They found that despite 95% of babies having their screening results documented in the electronic medical record, there wasn't an association with documentation and an actual successful follow-up process.

In a related article that wasn't a part of the 62 articles that we reviewed, there was an article looking at how pediatricians refer for specialty testing based on different risk factors.

That article highlighted that about 30% of PCPs do not feel that a referral on a newborn hearing screening should prompt a referral to an audiologist for diagnostic testing. We can probably agree that we have a little bit of work to do in this area.

Interestingly enough, the effects are variable. There is a significant amount of variability and the knowledge base that providers have. The articles address the fact that many pediatricians usually have a better knowledge base about hearing loss and EHDI versus family practice providers and therefore there is a variable factor whether your family goes to a pediatrician versus a family practice or general practitioner.

Lastly, along the lines of provider knowledge, we continue to find that there is insufficient or lack of quality providers or qualified providers for programs. This spans screeners, diagnostic audiologists, and EI providers alike. Care coordination has also been found to have an impact on follow-up.

We are going to talk a little bit more about this in the facilitators but for EHDI programs that have a specific care coordinator or navigator to shepherd families through the process, one study found that when they experienced time without this care coordinator, they saw a significant decrease in follow-up



rates. That is related to information gaps as we have already talked about.

When there is information gaps between the providers and the families, the families and their pediatricians, the families and knowing where to go. That all can hinder a family moving through the process. Overall, these are the main factors that we found that impact the entire journey. So now we are going to move on to specifically different time point issues. So, there are multiple approaches to screening across our country as you might very well be aware of. In some states, the baby receives only an inpatient screening.

Two screenings in the birth hospital and then asked discharge if they didn't pass the second screening they go right to a diagnostic. In contrast there are also programs that have inpatient to outpatient screenings meaning the baby receives 1 to 2 screenings at birth at the hospital and they also have their final screening that occurs at an outpatient clinic, health department, or PCP office. Some of these factors we found were related to one versus the other or just screening in general when we looked at our literature review.

The main issue or barrier for screening is really the quality of the screening. Many articles address the fact that data fidelity was a problem. Incomplete contact information complicates the outreach for follow-up that has to happen after a failed newborn hearing screening. They also found that programs with lower overall screening rates have a higher loss to follow-up. And programs that either have limited or no access to screening equipments, when you think about this in terms of home births or midwives who do home births, if they don't have access to the knowledge that they need to complete the hearing screening or the equipment, that often relates to having no hearing screening and then we have to follow-up or we have to rely on the pediatrician to make sure that the family follows up for even their screening portion.

The literature also suggested that when there is no audiologist involved in the screening program, it not only hinders the overall quality of the program but it also hinders the rescreening's that happened as outpatients. And then in programs where you might have a provider who is assigned to this program, if they have time or commitment restraints meaning that they are position is multifaceted and they are only allowed to have so much time to devote to the program, or if it is a low-volume birth hospital where you are only screening 3 to 4 kids a week versus 3 to 400 kids per week.

That often leads to lower quality screenings. Another screening issue is multiple re-screenings before the diagnostic phase. This is going to come up multiple times here. So many states have rules in terms of one or two screenings and then one or two screenings as outpatients but we hear time and time again families experiencing and getting three or four screenings at the hospital and then another three or four screenings separated by a lot of time in between before they actually get to a diagnostic assessment. That can make a major delay in our process. There was one article that suggested that having an outpatient step in the process can delay the process.

There is also flip sides to that that actually could be very facility already.

Families have missed or canceled appointments, but as we have talked about, sometimes that is



because they don't have transportation or because they have other responsibilities. It can also become – be because parental refusal. Anytime we have parents who refuse to follow up, it really often leads to significantly late diagnosis and significant developmental delays. Provider knowledge is also a factor for diagnosis specifically. We have already talked about this in terms of hindering the process of just getting people in for diagnostics after a failed newborn hearing screening. There are a number of articles that address the fact that some babies pastor newborn hearing screening but they have risk factors related to hearing loss.

And in the latest JCI age recommendations, recommendations for follow-ups change significantly as opposed to the 2007 recommendations. -- JCIH

Audit the risk factors listed, essentially none of them have a follow-up later than nine months of age. That is significantly different than the previous version which said follow-up at the 24 to 30 month age range. Some physicians are unaware of the certain risk factors that there are for hearing loss. Some of them are unaware that the schedule for following up has changed. And then in terms of provider knowledge there is also inadequate reporting happening.

There could be providers completing diagnostic assessments but not recording it to the state system. This is really loss documentation as opposed to two loss follow-up because the babies are having their testing but it is not being reported correctly. System-level factors for diagnostic barriers include multiple rescreening's as we have already talked about. There is a number of articles looking at the lack of evidence-based assessment or test batteries. This can really lead to incomplete testing, to establishing status and leads often to multiple tests that are needed to confirm results.

Sometimes multiple tests are required due to medical factors but sometimes it can be avoided if an appropriate evidence-based assessment is used. Inadequate scheduling and availability for patients to come in at convenient time points has been shown in the literature. As well as regular equipment issues or a sleep state issue for the baby not sleeping for the test. Those of us who diagnose hearing loss, infants know that there is a very small window of time that you can get a great diagnostic assessment and natural sleep in terms of age.

Then when you have a baby come in, they may sleep for 15 minutes or they may sleep for two hours and you never know that when you have the baby come in. When it comes to management and again, by management we are really speaking to the fact that we are talking about managing the hearing loss by some sort of device. If the family chooses to go through getting a device to manage the hearing loss, the number one factor that was a barrier in the literature was financial concerns. For some families, devices can be cost prohibitive. And every state has a different process. Some states, if you have a diagnosis of permanent hearing loss, your child is entitled to hearing aids at certain intervals throughout their childhood up to age 21.

In other states that is not the case. And other families have to rely on their private insurance or qualifying for Medicaid or if they can't or don't have a private insurance that covers it and they have too much income to qualify for Medicaid, they have to rely on private funding sources that are often hard to navigate in terms of applications.

Additionally, the type and severity of hearing loss has been found to be effective. It fits with mild, unilateral or conductive hearing to be fit publication, despite the need for it. For the past 10 to 15 years, there has been data to show that children with mild hearing loss for unilateral hearing loss due to manifest with language delays, cognitive delays, and other delays that impact their academics. We still see a residence to fit these children at the outset whatever reason. It can impact the appropriate management of hearing loss from the onset.

In terms of family factors, we often have base and canceled appointments. Again, this can be often related to family obligations, employment times, and lack of transportation. Sometimes family acceptance becomes a factor here. Families need a little bit more time to come to terms with the diagnosis.

Lastly, system-level factors include appointment availability, and this is really specific to either the availability of having a hearing aid evaluation or fitting appointments might be constricted, because of specialty appointments needed, the appointment needed medical clearance for vacation in children.

Both of those things can protract the process, but it really gets protracted when those types of services are not actually double in the same geographic location. If a family gets medical clearance locally, but they have to travel for hearing fitting from a pediatric specialist, that my protracted process.

Lastly, families have reported in the literature that there is inequality-- inadequate audiologist or insufficient information provided and information about the process in general that hinders management.

Lastly when it comes to the eye enrollment, medical factors are what typically attracts this. --Ei.

The type and degree of hearing loss can impact whether a child gets early intervention. We know that children with mild unilateral hearing loss are less likely to be enrolled in EI, and that is likely related to the fact that many EI services are related to development Tony. Children with mild hearing loss might not manifest the type of delay that speech and fiber skills that children who had performed hearing loss. It might take them more time to see those delays. Same with you.

Often children with unilateral hearing loss do not have ways in expressive speech production, but they have other delays that manifest later.

This speaks to the fact that our programs, many of our programs, and this might be different depending on your state, but we really functioning a failure based program. Failure based state. We wait for the kids to meet to qualify for intervention, before we proactively provide it. That really causes an issue with enrollment.

The other areas that are related to EI enrollment are just family choice. Many families choose to wait to April, or they seek out private EI services and don't report it to their state program so we do not know the children are getting private services.

What have you are so far this morning? We have gone through a lot of barriers. We know that barriers exist for time effective the HDI. Some of those barriers happen for all steps of the process, and some are only specific to particular steps like funding for implication, or not enough qualified EI providers.

We have also seen the social determinants of health have significant impact to the success of our EHDl programs. Review, we some evidence to the contrary. Some studies, social determinants to health were not the factors associated to delays or loss of follow-up.

Be found in one article by (unknown name) and colleagues, that public insurance status was not associated with delays in diagnosis, management, EI ambulance.

An article by Smith and colleagues developed a medical facility in three different states, not of the SCS factors that they studied related to delays in treatment of hearing loss the speech, outcomes, hearing aid (indiscernible) Airbus to follow-up.

They found children on Medicaid access to services, and similar outcomes for speech and leg was development, which is really promising. That is not what the rest of the literature shows us.

Lastly, (unknown name) and colleagues, (indiscernible) and that it related to having multiple children of the family. They had childcare needs and family operations. Or it was Nick Tuesday. The maternal education, or the city, really contributed to that significant difference and follow-up.

He begs the question of why are these three articles different than the rest of the literature?

What the commonality is across the studies, is that they were all completed in settings where system-level or hospitalwide programs were in place to potentially mitigate social determinants of health.

In the (unknown name) study, they were at the Metropolitan Children's Hospital. They had eight sites in the Metropolitan in adjacent areas. They were proactively addressing the access issue by having specialty services available at different sites.

The Smith article, there were three major metropolitan health facilities in different states, and all of the very large population. Their hospitals took under programs to facilitate healthcare in those families.

Lastly, the (unknown name) called took place at an urban safety net hospital. By definition, those hospitals are mission driven to provide services regardless of the ability to pay, or insurance status.

In that article, it is likely that taking out if the barrier of cost for insurance actually helped those children move through the process more effectively..

We know the social determinants of health can impact it, but this gives us hope that we can mitigate them by having system-level facilitators.

So at this point, we are going to move on to facilitators. Before I pass it over to Doctor Hunter, we are going to do what more pole--poll. This is how you reach the pool. You can either use your smartphone. Don't answer just yet because the pole not be activated on to the next slide.

If you can tell us what facilitators you have identified to help our families move through the one – three – six process. It will be interesting to see what we have here.

I will just wait a minute, and hopefully people were able to navigate back.

Family, mentors, phone calls, strong state fornicators, parent support. Very important.

Lots of support and education.

Family and parent support, yes.

Mentoring, coordinators, language.

One consistent... Bo. Consistent communication. These are great.

These are also facilitators we found within our review.

So, I at this point Emily deposited over Doctor Lisa Hunter, to look through all of our facilitators. I am to stop my sharing. It says new share. Did you take over? Stop sharing. There we go!

LISA WEISS:

Boat--

SPEAKER:

Discards the stage for us talking about facilitators. Let me go to share my screen. Same way to put it into presenter mode so that it comes up properly.

Can you see my sled OK now?

URSULA FINDLEN:

Yes, we can see it.

SPEAKER:

You are hearing a big theme today.

I am Lisa Hunter. I am at Cincinnati Children's Hospital Cincinnati, Ohio. We are having beautiful weather today after two days of storms. I am happy about that.

I am the research director for audiology here at Cincinnati Children's Hospital. Like Ursula, I have a political affiliation with the University of Cincinnati in both (unknown term) and audiology. Just a fun

fact about me, I started my career in my CF why doing targeted screening in the NICU here at Cincinnati. This was before the days of universal screening. It has been really fun to see the progress across the whole country since then.

I was then able to get additional training in Minnesota, as we were starting out newborn screening just around the turn of the last millennium left.

I then want to tell. I got to see some really great EHDI program in action. I have been thrilled to work with people like Ursula, and the rest of the people who are so passionate about EHDI Ohio, to see if we could continue moving the needle in each of these areas.

The theme of the barriers, I think what really motivated Ursula to bring up this question of "Where are we with both barriers and facilitators?" Do this in a systematic way across the EHDI journey, is the social determinants of health question. This comes up not only for barriers, but facilitators.

What has been really great reading articles, is to see how people have been able to take knowledge about the barriers, and put into practice some specific interventions that may help address some of the social determinants of health.

You have education and language barriers as we see in the part of the graph here, or whether that is access to healthcare coverage, and access to local early intervention services.

The build community, whether you are in a rural area or suburban or urban area, those are going to look really different and need to consider those different factors of distance, accessibility to care, and who the providers are, especially for families that are choosing different communication strategies for their children. They have access to that in their own area.

The social support around the family. Not only their family, but the social support from the neighbors and friends that surround the family, and then of course what they have available to them in terms of financial supports are all important and considering what can facilitate their journey through the EHDI process.

So there are some great resources to help, and not only all of us as EHDI providers, but also the families in learning about hearing loss, because many of us work in a particular part of the EHDI journey, whether that is the screening part of the program, or has diagnostic audio just, early interventionists, or physicians that help families through their whole medical process.

It is really important that we think carefully, especially about the transitions between each of these sections from birth, four-month, screen that may have been, and other diagnostic process in getting families intervention. It looks a little bit different with each one stages. It is a wonderful resource at (website) to look at that map.

Another resource to help families across this journey and connecting across silos of care is Hands and Voices. I know the team is one of the facilitators.

Ursula kept talking about this parent to parent support, and how important that is at helping families to get across those different stages.

So, many states have their own hands and voices chapter, there are also provisional chapters available in some states, and nationally these resources are also available for families. That is really making a big difference.

When we are thinking about the entire EHDI journey incarnation, one facilitating factor that came up in some articles is care navigation. I know we are lucky at our children's hospitals to have an audiologist whose full-time position is dedicated to care navigation. But a few hospitals are developing these processes where they can help shepherd families through the entire process of EHDI, some families have a go to person that they can contact at any step of the process to say "Hey, I am really having trouble finding an early intervention provider in my area who is able to work with the type of communication that I want to have as a family."

That care navigation is really critical. This is a nice place to co-locate her lease to be in communication. Those families that need support. In different states, this has been tried and is working well. Coming back to the familiar birth nursery for the outpatient screening if that happens is important.

They are not going literally to a different place so it is not sort of 1/4 step in that three step process to go to a different hospital than the one that they were used to where they gave birth. That can also be a great facilitator.

Hospitals that are screening proactively schedule appointments and really connect with the diagnostic services in their area to make sure that there is a priority for getting infants in as quickly as possible. For either rescreening or for diagnostics.

That can be done at the time of the newborn screening referral and there are a few states that actually require this and that is something that could be considered in states as either requiring or strongly encouraging and making it possible to have a system where that can be proactively scheduled.

Linking up the EHDI data can help reduce data entry errors and also facilitate contact information. A big issue that can come up is that families change phone numbers, or they change addresses. This is quite common after babies are born. That is a time when families are often moving.

Having that facilitation for contact information makes a big difference. Linking EHDI data to other data management systems like for Medicaid billing or some states are linking up with services so they can keep in contact as the families are going to EDHI clinics to identify documentation. If audiologists are involved in the process, they can really help to ensure quality of the screening program and a lot of that comes through education.

We have non-audiologists, screeners often turn over very quickly and may not have as much

education. Having an audiologist you can be that go to person to help with counseling, strategies, information for families is really important.

Having access to really good and up-to-date equipment and especially when there are home births which are increasing, having that equipment available for midwives can make a big difference. Positive social support for families.

Making sure that we are asking at the hospital level are there any barriers that might prevent you from following up and getting the diagnostic.

That is a really great way to ask this. Are you going to be able to have transportation? Do you think that you will have any difficulties scheduling this appointment given your work or school schedule?

Do you have any financial concerns that may prevent you from following up? Asking those really specific questions and providing social supports that are needed for families can help minimize data loss follow-up impact. For inpatient only screening programs, as Ursula mentioned, this can be a facilitator in that it can reduce a possible pinch .4 loss to follow-up because they are having to not make yet another appointment if both screenings were done in the same hospital.

However some say that some have inpatient and outpatient programs because they have for structure in place to make sure the children are not being lost to follow-up by having to find yet another place to get rescreening before they go on to diagnostics. That is really the critical key.

Thinking about it and planning for it. Financial concerns can be a burden. Families may not expect to have a bill from screening services but sometimes that happens. Some EHDI programs have put in a safety net where they serve as the payer of last resort for screening and diagnostic services. Then, having a known payment pathway with reimbursement can help reduce and make sure that families are not reticent to follow-up because they are concerned about the cost. In terms of diagnosis and outreach, and this is accessibility facilitation. Having tele-audiology services has made a difference in the articles that we reviewed that have that available.

And outreach programs were said children's Hospital goes out to outlying areas to reach people that are in otherwise underserved areas. This is something that has been looked at and we saw some articles by Matt Bush in Kentucky for example, looking at how to facilitate that with local audiologists and another idea is educational audiologists locally can help reduce that loss to follow-up when families have trouble traveling to a distant diagnostic location.

Partnering with local physicians. The audiologists and physicians know each other and they make sure that they confirm the follow-up appointments and also send the results back to the physician.

That really helps with loss to documentation. Then continuing. Discontinuing. We can't stress enough that we have to keep providing that education, it is so important to follow up sooner rather than waiting. For that referral. And not minimizing the importance of following up.



Tailoring the family education. A lot of you mentioned that language was a barrier. So tailoring this by having the follow-up information available in the languages that are prevalent in your community is really vital. Also making sure that if possible, the family to family support programs that we have include families from different backgrounds. Actively recruiting families that speak different languages. To help provide that family to family support is really vital. Also, having positive social supports. Having those positive role models from other families who have been to the process. War can help by saying I know this healthcare provider in your area. That can really help with better follow-up as well.

For audiologists it is really important that we look at our diagnostic protocols in an ongoing basis. This is something that we have been doing in Ohio where we are really looking at evidence-based diagnostic protocols to make sure that we have more thorough testing the first time a child is seen.

Also, making sure that audiologists know how to make a really well-prepared baby and how to use best practices to make the incident sleep so that families are not having to come back for second, third, or even more diagnostic follow-ups because the baby wasn't able to get through that diagnostic process the first time.

Audiologist knowledge. The audiologists that are may be in the more outlying areas may not see as many babies. The more babies that you see, the more diagnostics you do, of course the more familiar you are and the better the services are. Providing outreach for training programs for pediatric cardiologists who may not see as many infants can really help with getting better diagnostics.

And of course having more up-to-date instrumentation technology, that is an expense but it helps to offset a lot of this repeated testing and then perhaps having to refer the family in to a bigger diagnostic center because we don't have the access to the right kind of equipment that can just really facilitate not only faster but more accurate diagnosis in the end.

And then finally having a plan for risk factor monitoring. We have seen a big improvement in the percentage of families here locally for following up and it is because we have gotten better. As putting in specific risk factors and partnering with physicians. So they know that this baby is going to need to come back even though they passed newborn hearing screening. Because they have these different specific risk factors that require follow-up at older ages.

Ursula mentioned hearing aids as being an important factor in terms of financial concerns. So, programs that can provide loaner hearing aid programs until funding can be put together for a family and of course states that have the ability. In Ohio, we have a program that will cover the first set of hearing aids for children so that that is not a barrier. And a number of states have those programs. That is enormously helpful so that there is not a delay.

And families aren't suddenly hit with thousands of dollars that were unexpected with their newborn. So parent to parent support is not something that we can say enough about. Speaking with and learning from other families makes all of the difference. As professionals we are giving them the education and the information and the technical assistance that they need for diagnosis and early intervention. Families have that lived experience that we don't have unless we happen to have a child with hearing

loss and so that is often – families don't always know to ask for that.

That is the most common resource in retrospect. Once they have been through a few years and the journey that they say I really wish that I had met other families of kids with hearing loss earlier. That would've really helped me. And then in the absence of standardization, each state is going to be a little bit different. The laws are different.

Differences across states in terms of Medicaid coverage really do impact programs, or really impact outcomes. Having evidence-based national standards for EHDI like we have with JCIH and adhering to that as much as possible helps to drive better outcomes. We see that degree of hearing loss makes a difference. Children with profound hearing loss are more likely to be enrolled. Children with mild or unilateral hearing loss are less likely but the data are showing that they are just as likely to have adverse outcomes as children with more moderate and greater degrees of hearing loss. Other issues, comorbid medical issues because more likely poor outcomes, which can – they have multiple needs that need to address. JCIH provides us with national guidelines but each state may differ in terms of execution but that can impact the outcomes.

So there was article by Kingsbury on social determinants of health reviewing this and we really need these universal standards to try to reduce variability across states and over time. So. Social determinants of health and other individual factors, we have found overall, service barriers while system-level changes have been shown to be positive facilitators of EHDI. Some system-level changes have served to mitigate social determinants of health so our role in EHDI is to apply these system-level changes in order to mitigate these. And urban versus rural considerations show us that we need different types of changes for different needs. It all comes down to meeting the family where they are. Co-locating services I have mentioned.

Well Child visits, designing tele audiology -- Tele audiology, training professionals and those underserved areas and tapering materials to the level of families is a primary way to address meeting families where they are. Some limitations are that most of the studies were not randomized controlled trials. Actually only one study that we looked at was. This limits some of our conclusions in terms of the biases and selection recall and that sort of thing that can limit generalized ability. -- Generalizability

We only included studies in the United States due to specific factors for the US and we have a lot to learn from other countries. We can look at that especially for designing facilitators and systemwide changes. So we need more research, we need to understand management and we need to look at early intervention. You can see that most of our studies have been in the diagnostic phase or screening. We really need more studies that are looking at facilitators for early intervention enrollment.

We need to expand our understanding of family support and parent to parent support on the journey. And we need to understand how these different factors interplay in the interaction between them. So with that, I would like to pause and I hope that we have some time for questions. Ursula has her email address appear if you have questions. And generously her phone number as well. (Laughs) We hope that you will reach out and we are really happy that you were with us today. Thank you.

URSULA FINDLEN:

Thank you so much, everyone. We want to first give a large shout out to Laura, our ASL interpreter who has been going strong for all 60 minutes. We thank you so much for keeping up with us and our very – a lot of information was shared.

There was one question in the chat about sharing slides early on. I am happy to share slides. I don't know if I can just have them sent out to those who registered. I will make sure that we can try to do that. I know that we are running up on time so we might have to go to email for Q&A. I am not seeing any other Q and a in the Q&A box. So...thank you so much for this opportunity and thank you for your attention today and please follow up with us if you have any questions.

SPEAKER:

Thank you, Ursula. This presentation has been recorded. It will be made available within 3 to 4 days. There will be a survey when you leave the room that you are welcome to fellows to receive a certificate of completion. And if you could give us some feedback we would appreciate that. I will leave the room open for 2 to 3 minutes and I will say goodbye. Then, we will close it.

URSULA FINDLEN:

Thank you.

LISA HUNTER:

Thank you so much, Laura. You are fantastic.

URSULA FINDLEN:

Thank you so much.

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