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Topical Session 7 & 8: Capitol 5

March 19, 2024

1:45 PM – 4:00 PM (MDT)

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1:45 PM (MDT)

[Captioner standing by]

>>: All right, everyone.    We will get started.    Does anyone need interpreting services?    There is discussion downstairs, so we may wait a few minutes to see if any come in.    For now I will pass the microphone over and we will get started.

KARRIE HUGHES:    Hi, everybody.    I'm so glad you guys are here.    I wasn't sure if anybody would show up so I'm so glad you are here.    I know some people are trying to get on flights and get back home.    My name is Karrie Hughes and I am with Hearts for Hearing, Oklahoma City.    We also have a clinic in Tulsa.    This is our building in Oklahoma City.    We have pediatric audiologists and speech and language audiologists and we see kiddos from newborns to adults.

If you are ever in Oklahoma City, come see us.    We would love to have you.    Today my objectives ‑‑ I will talk about the loss to follow‑up.    That has been a topic of conversation in a lot of our talks in this conference and I'm going to go a little deeper into the loss to follow‑up.    My objectives, I will identify to barriers to not just beginning a newborn hearing screening but also overseeing, because I know most of them have already started unless they are a brand‑new hospital.    Is anybody doing screening in the hospitals right now?

Wonderful.    That's great.    And then everybody is overseeing newborn screening in some capacity?    Wonderful.    We will identify three components, more than three, for successful newborn screening.    And then identify two strategies for successful communication with the state EHDI Program.    I just want to talk about my background.    I was a NICU nurse for 12 years, loved it, I was in a level three NICU fast‑paced, and I remember way back when, I am old, what audiologists used to come in and they would test the kiddos they were on Gentamicin and a little bit later after that Jim Smalls, our state coordinator, came in with an APR device and said I'm going to train you guys how to do hearing screens and we were like, oh my.    When are we going to have time to do that.    So as a nurse's perspective, it was hard to find the right time and to do good quality screens on a newborn.

Our referral rate was awful.    It was 9%.    We were slamming the audiologists with babies that did not need to go there.    So long story short our neonatologist decided to outsource our newborn hearing screenings and that is where my love for newborn hearing screens started and I actually changed tracks being an RN and all of a sudden I'm now doing newborn hearing screening and I have not looked back.

I have been in newborn hearing screening since 2001.    I have loved every minute.    I have an a lot of task forces, Colorado back when Marion Downs was here and it was exciting times.    Back in 2020 at Hearts for Hearing we decided to take a step back and look at our state and look at what is happening in our state.    Some of our pediatric audiologists were thinking are we really capturing all of the babies that are having hearing loss in our state and the number seemed low.    It was during COVID and we did a deep dive into the numbers and we looked at the CDC numbers are you all familiar with that everybody has looked at the CDC numbers?    If you haven't I highly encourage you to do that.    One of my favorite ones was looking at the national, the first 100 data statistics, and what we did is we compared our states to those national numbers line by line.

That is what really popped out at us, yeah, we do have some areas for improvement that possibly Hearts for Hearing could help out with.    One of the first things we noticed was our loss to follow‑up was high, almost double at the national level.    Also the incident was 1.4 and that lined up with what the audiologists were thinking that maybe we are not catching all of our newborns that have hearing loss.

We have about 48,000 ‑‑ this year was 2018.    We had 71 babies that were diagnosed with hearing loss.    Also we have parents show up at the clinic with their audiologists and they had a missed screen at the hospital or they were home births and they would come in and then we had some nursing friend start calling me at the hospital saying our referral rates are high.

What do you think?    I know you are in newborn hearing screening, why do you think this is?    There was a lot of discussion at that time in 2020 and again, we were thinking maybe we were having more and more late identify kiddos with hearing loss.    These are our national numbers and I don't want to spend a lot of time on this because in our state our state has gone back and fixed some of these numbers so I don't want to spend too much time on this.    Again, we thought what can Hearts for Hearing do to help improve our states lost to follow‑up.    How do we knock it back down to where it needs to be, zero or just a little over zero would be great.    Some of the things we thought about was how about start and inpatient diagnostic testing on these NICU kids who ‑‑ two quality tests and have the audiologists go where the babies are right now.

That will help the loss to follow‑up so that is what we did and that is what we started was inpatient diagnostic testing and if you can do that, I'm telling you it is a gold mine because these kiddos are in‑patient and if you find out they do have hearing loss you can have an ENT consult and do imaging before that baby goes home and that is what is happening today in our busy NICU's.    These kiddos are getting imaged if they have hearing loss, right away.

That help speed up things.    Another thing we decided to do was start an outpatient rescreen clinic.    We would have the babies that were born at home come into our clinic to get the test done or some of the hospitals during that COVID times were not allowing babies to go back in to get those repeat rescreens so we thought hey, they can come to our clinic and we will screen them there.    Another thing we looked at was let's start newborn hearing screening and let's help the state and get our hands around this.

Let's follow those newborns until they are diagnosed.    Don't stop until they are diagnosed.    In 2020 we started that inpatient diagnostic testing, so it could be nurses screening, another vendor screening, but what we did was talked with a neonatologist, nurse directors, and said please let us know when you have a baby that refers two times.    Our audiologist will come up and do diagnostic testing right then and there.

2021 we started screening in the clinics and 2024, Q4, we started our first newborn screening program at two hospitals.    This is over screening protocol and adding in diagnostics.    This is what it looks like and it is still two one, two screens in the hospital and one outpatient screen for well babies.    In the NICU that is where we are looking at bringing the audiologist in the NICU and getting those kiddos tested.

It has helped so much.    We have kids that live far away and they might not have come back in if we ‑‑ if the audiologist says your baby has hearing loss.    To have that definite diagnosis before they go home has been a game changer.    A couple of barriers with starting the newborn hearing screening, one was obtaining the hospital contracts.    We had never done it before and Hearts for Hearing had never been in that realm, so just allowing our community to trust us to come into the hospitals and start screening their newborns was our first barrier.

And then of course insurance reimbursement, that is always fun.    Building a data management system.    You know, with building that, you have to have a data management system when you are newborn hearing screening.    You have to see what is coming off that device and pour through that data because you are going to find is you guys all know you will find over screening or find only one screen done or find a be a baby was screen under the wrong information.    There is all kinds of things you have to look at and having a data management system, you can look at quality assurance, what screeners have a high referral rate, so you can do reeducation.    Building a data management system is key.    We are so lucky in our state we are working on getting that data from the machine into the state database so there is no human error and we are working on that as we speak.

Hopefully that will be done pretty soon.    Some of the components of a successful newborn hearing screening program and these all play into dropping that loss to follow‑up rate is educating your staff.    Whoever is screening those babies at the bedside, parents attention and they will be educating that parent on newborn hearing screening and another thing I have found out because I had not been doing the screening in many years, I found out that the nurses, the new nurses don't even know why we are doing hearing screens.

That was an eye‑opener for me to oh my, we're going to have to start educating the nurses and even the neonatologists, the new ones, that were in the hospital.    I started pulling them over, come here I want to show you what a newborn hearing screening is.    This is why we are doing this.    That was eye‑opening to me to know you think 20 years of knowing about newborn hearing screening, some of these nurses just stepped into the NICU.    They have never even known about a newborn screen.    So educate educate educate.

Another thing that is important is doing those screens at the bedside because you have moms undivided attention right then and you can tell her all about a newborn hearing screening and the purpose of why you are doing it, and really engage that family.    If the baby fails that screen or refers, give them clear directions on the next step.    Make sure they understand okay, you are going to come back to this hospital and we will do an outpatient rescreen at this time.

If you have any problems here is my phone number so we can reschedule that appointment.    That helps tremendously and also doing it quickly.    Do it in five to 10 days.    Don't wait a month to do that outpatient rescreen because you will lose them.    They will think own no big deal, they will hear from their friend down the street that my baby did not pass either, my baby can hear just fine.    They will hear all those things, so it is very important to get them back in as fast as possible and their numbers change of course in their addresses.

Another thing, while you are at that bedside making those appointments with the families, ask if you have any roadblocks or if there any obstacles about coming back to the hospital or coming back for the rescreen.    Sometimes we have 15‑year‑old moms that don't have drivers license and how are they going to do that when their mom works full‑time so we have to meet them on their level.    If they can only come in on Saturdays we're there on Saturdays to do that rescreen.    If we call ‑‑ we always call the day before and remind them of appointments.

If they don't show up immediately call them because you are already there.    If you are stuck in that time right there for that baby, if they don't show up in 15 minutes, hey, are you guys coming, you can't come for another hour, no problem I will see you in an hour.    Do whatever you can to meet their needs.    Then hold onto that family.    Make sure if you do have to schedule an audiology appointment ‑‑ I don't know how this would work or if you would find hospital, like a nurse, that would help with those phone calls to help with the outpatient rescreen reminder calls, but there's probably some of that we do that at the hospital.    Ask.    It doesn't hurt to ask.

Some of those nurses may help out with follow‑up calls.    Always always always aim for the loss to be zero.    You can do it.    We can do it.    It is more work and it is hard, but it can be done.    Here's our data from the first year of our newborn hearing screening.    We screened 8400 babies and our final referral rate was just right at 1% just below 1%.    We identified 27 babies with permanent hearing loss which the incident was 3.18.

I know this isn't a lot of babies, but this is a 3.18, it is what we are thinking.    If you remember back in 2018 we only identified 71 babies which is 1.4 incidents out of 1000 and this is 3.18.    You know, there is the other ones right there.    Then we had a loss to follow‑up.    Okay, from the day we started newborn hearing screening until the end of the quarter of ‑‑ gained more hospitals and we are now in the 14 hospitals in the state of Oklahoma.

We have screened 28,000 babies.    Our final referral ‑‑ these are babies that have gone back for outpatient screening ‑‑ we had 281 and our final referral rate was just a little bit below 1% and our capture rate was 100% and their audiology result of the 28,000 babies we identified 76 with permanent hearing loss which is an incidence of 2.66 but we still have 52 babies that have either come back in and the audiologists have diagnosed as inconclusive.

They were not quite sure yet if they had hearing loss and need them to come back.    Maybe it was fluid or they had middle ear, so we still have 52 out there.    Even if we get a quarter of those babies we're hitting over three out of 1000 and our state.    Right now zero lost.    We are doing every single thing we can to make sure we get a hold of those babies and it is a whole state effort.    Not just Hearts for Hearing audiology.    It is other audiology groups, the state, all of us together that have made this possible to keep this zero loss.

We are all working together.    That is what this slide is about.    It is a collaborative effort.    You know, I feel like in our state we don't have any silos.    Everybody's working together.    If I have a baby that the mom was the very first appointment right away and another audiology group has a faster appointment, by all means what is best for the baby is to get that baby to the audiologist faster.

The babies don't have to come back to Hearts for Hearing.    The key is the baby gets somewhere, and if they live far away it makes more sense for that baby to go close ‑‑ Debbie Early, our state audiologist, she travels and we work very closely with her and, hey Debbie, we have a baby that lives three hours away.    When are you going back down there?    Can we schedule?    Or answer is always yes.

We have an audiology group in Moki that the baby is closer.    You have to meet the parents where they are or you will lose them.    And stay on them.    We had one baby the just recently we touched them 25 times before they were able to come back in.    We called, we called again, we called the pediatrician, we call the state to see maybe there is a new number or the pediatrician had a new number and we did not give up and that they became back in.

There's lots of stories I can tell you about that ‑‑ I will tell you one really fast.    We had a baby that the screener had been back and forth to the mom's room and she had other babies to screen so she was checking on the mom, baby was crying, baby was breast‑feeding, she went back and the baby was gone.    So she went back to the nurses station and was like where is that baby and they said they are wheeling her down the hall right now.

They stopped the baby and mom brought that baby back in and that baby had hearing loss, bilateral.    It is stories like this.    You can't let one of them get out of the hospital but also that follow‑up.    You can't let one of them get out the door.    That is all I have.    Do you have any questions?

>>: I'm sorry, I came in late.    I am wondering how you were able to look at your typical birthing demographics or if that was helpful at all?    I'm in South Dakota and we are trying to look at average age, income, education level, to see if that helps us with techniques to get in touch with them.

KARRIE HUGHES:    That is a great question because I know where you are going with this.    This age group they text.    They will not listen to their phone or answer the phone.    They are not going to listen to voicemail.    It is all about texting.    I think in the hospital making that appointment before they get out the door is very important and make sure they have your number and make sure you stress the importance of call me if we need to change this, but it is very important you come back as soon as possible.    Does that help answer?    I think one day we are going to have to look at do a Facebook message, we do LinkedIn.

It is going to get to that because they will not be texting.    They will not be doing that anymore.    We have to be on that forefront and meet them where they are.    One day it is going to be a whole different ballgame again, but they are not answering the phones anymore.    It really helps if you know the pediatricians.    We always get the follow‑up pediatrician in the hospital and we make a note of that.    Who are you going to after the hospital, and get that name.    That is key because we call that pediatrician, we can't get a hold of them.    Have they been coming in?    Here they are.    Do you have a better number?    Can you tell them to come back to us as soon as they come in at the next baby check and that has worked in 25% of the cases.

It works really good for the overall loss.

>>: How is your relationship with pediatricians?    We have found in Colorado Springs that we still have got some of the dyed in the wool, oh, it's nothing.    Wait until they are two type of things.    We try to work a lot on education because of other young ones.

KARRIE HUGHES:    That is a good point.    One thing with the nursing staff, I make sure I'm telling them don't tell the parents it is just fluid.    Don't tell the parents the equipment is broken.    Those are key things.    With the pediatricians, I would pick up that phone and call them and say did you know the faster the better?    Maybe if you have another pediatrician ‑‑ state champion ‑‑ if they contact peer‑to‑peer that might work, too, but I have had those pediatricians that told a parent to wait until the baby was one year old and I was like, oh, my goodness.    No.

It is difficult.    If you have those uncomfortable conversations that will help.    They just need education, that's all.

>>: Thank you.    I wish I had had this presentation 13 years ago when I developed a brand‑new hearing screening program at the hospital where I still am.    I did it blind.    It has been a process.    I wanted to make two comments.    All of our pediatricians will not discharge a baby without their hearing screening results in the system so I don't have to worry about that.    But also because I have ‑‑ I live in the D.C. area and we have a diverse bilingual, multilingual community.    When we place phone calls to the families we do it in their language.

I find instead of leaving a voicemail in English, most of our people are Spanish‑speaking and all of my technicians that do the screenings are Spanish‑speaking so even if I'm talking them through the phone call and what to say I think it really helps our loss to follow‑up rate, but I can't believe you have zero.

KARRIE HUGHES:    So far so good.    We are trying.    We are not giving up.    That is amazing what you are doing.

>>: Two more minutes.

>>: I have a question for you and anyone else who has started a program or screening.    Who is doing or screening typically?    In your state is it screeners, nurses, audiologists, and how long are you spending doing the training for the various screeners?

KARRIE HUGHES:    That is a great question.    As far as the training, I meet the screener on their level.    If it takes the screener two weeks to learn how to do it, we have a competency checklist and they have got to meet that competency checklist before they are allowed to go on their own.

We mainly have screeners and we have students, a lot of audiology students speech in line which pathologists that work for us, a lot of college students or retired teachers.    They are really good at education so they are the perfect fit.    In our state we are in 14 hospitals so we are a vendor that the hospital's contract with.    The other ones it is the nurses that are doing it.    I thing there is one other vendor in our state, too.

They are not ‑‑ I have gone to those hospitals and talked to the nurse directors and managers to get those programs in the past and if you're not looking at the data, they are over screening or screening that may be eight times, you know?    Volunteers are great if you have some really good ‑‑ but even with nurses, we were doing not a very good job with doing it.    You have so many nurses and everybody has a little bit different way of doing things, but if you have it focused as a group and they have trained and they get competencies every year and we have staff meetings and talk about the loss to follow‑up.

>>: I think we have one more question.    Just be respectful of the next presenter.    Would you mind talking out in the hallway?

>>: To pinpoint on that, I'm the newborn screening program manager for Oklahoma so I oversee blood spot and hearing and Hearts for Hearing is the largest vendor and they do an amazing job and we have a total of 44 birthing hospitals so they are in 14 and they do have the largest hospitals in the state.    We work very closely as Karrie had stated in the other hospitals as far as we don't ‑‑ don't have any hospitals with volunteers.    They are all nurses or screeners that are private by the hospital.    We also provide hearing equipment to those hospitals that do not have a vendor.    So we know they are getting calibrated and they have what we want them to screen with.

KARRIE HUGHES:    All of our screeners go through the NCHAM training but all of our staff goes through that training and is certified.    That is the first thing they get taught on is to go to NCHAM, takes two to three hours.    It is well worth it.    Very good.    Thank you.    And if anybody needs something here is my contact information if you want to talk about newborn hearing screening.    Just call me.    I love newborn screening.

>>: How are you?

[NO AUDIO]

>>: Hello everyone.    It is 2:15 and I want to check and make sure we have interpreting needs if needed.    Anybody here need interpreting?    Perfect.    All right.    I will pass the microphone over and will get started with 2:15 presentation.

RANDI WINSTON‑GERSON: Good afternoon, so nice to see you all here.    I am Randi Winston‑Gerson.    I am the program manager for the newborn hearing screening training curriculum at NCHAM and the virtual site project.    I would like to introduce you to my partner, Stacy Jordan.    Today we are going to be presenting on the newborn hearing screening training curriculum the community partners version and this has been version of the curriculum that has been planned and in progress for a long time and we started it may be four or five years ago but then we were waiting for the new joint committee on infant hearing position statement to come out and then we updated the current curriculum to have all the new best practices and we had to put this on hold.    So here we are and we are finally at a place where we can show it to you and say we are moving forward very quickly.    Just a little bit of a financial disclosure, nothing much here.    We do not have ‑‑ we are not endorsing anything in none of the materials are intended to endorse any particular screening equipment system or anything else.    I always like to acknowledge content development and I think she's in the room, she helped with the content development as well as Ginger Mullen.    The review, we ask core state programs to review the content before we actually decide if it was completed and they offered a lot of edits and we fortunately were able to implement most of them.

We did our videotaping on Sunday here in Denver with a midwife who was so gracious to invite us into her practice, with four of her families.    We are done with that and now we move on to the development of the e‑learning portion of the curriculum so the just, the objective is to improve the standard of care to babies and families for screening and follow‑up through efficient practices resulting in quality conference of standardized training.    This goes across the board to pretty much every project that we are working on.

Just a general overview for those of you who are not familiar with the current curriculum, it is an online competency‑based course or hospital screeners.    We have it available in (Indiscernible) e‑learning platform and HTML which is a version that anybody can go on the NCHAM website and watch it.    No problem.    You don't have to sign up for it or do anything else.    It is web‑based, user‑friendly, self‑paced.

There are eight modules for hospital‑based screening and that is because it is such a comprehensive program, so we had to make this curriculum very comprehensive to really provide training and education on all aspects of the newborn hearing screening process in the hospital.    Here are the eight modules that we currently have.    We offer a recertification test that we recommend people take once a year and we also have a certificate of completion we offer.    There's lots of resources, scripts, videos, self checks, and CEUs.

We have had over 30,000 enrollees in the curriculum and that is a lot.    As you can see over the last two years that number has increased to closer to 5000 people per year that have enrolled.    We feel like it is getting out there.    We just shared it with South Africa newborn hearing screening program.    We are very excited that we were able to provide it to them and they will use it in their program.

Who are the community partners?    The community partners refers to any non‑ hospital‑based outpatient newborn hearing screening program.    It could be midwives, birthing centers, out of hospital births, home births, providers of medical care such as pediatricians, community health clinics, also we could provide this to an early intervention program that is seeing newborn babies but to be very clear this is only about newborn babies.    Nothing beyond one month period.

Why did we create it?    Because it is the content that is needed for this type of a setting and it's very different.    Not very different, but different enough.    For the hospital‑based we had eight modules.    For this we only have five and I will show those to you in just a moment.    We were able to streamline the curriculum to really create what was necessary, for example, a midwifery practice.    It is very different then screening in hospital.

We know a lot of midwives have been using the hospital‑based program, but we have had so many requests over the years for something that would really be geared for a midwifery or homebirth out of hospital setting.

We also wanted to provide any programs with a standardized solution for this type of setting because I don't think there's anything out there for outpatient screening, especially like in a pediatricians office and so on and so forth.    I think there's definitely a gap there in what is provided for training.    It also connects community partners with a EHDI program.

We really do bring the EHDI program to the screener that is in an outpatient setting and they might not have access to EHDI and they may not even know what it is or that there is a state EHDI program but we really try to make that happen in this curriculum.    Stacy, I forgot to tell you to jump in anywhere you want to.

And don't even just say Randi, Randi.    Here are the benefits from how we see it.    For one we should be using a curriculum.    We need to provide a standardized training tool that we know that screeners, if they take it and they become comfortable with screening, their confidence level is going to increase and that is going to improve their practice and how they screen babies and feel around holding babies, touching babies, screening them, holding their hair back, they need training.

It also helps to (Indiscernible) lost to follow‑up.    We provide scripting for effective consistent messaging to family.    That is so critical, especially in this kind of setting because they could just fall off the radar.    We have to have a mechanism for a handoff and follow‑up, a very strong sense of follow‑up purpose.

We also think that providing parent education as part of this is something they may not get otherwise and, again, the awareness and connection with EHDI programs is critical and huge benefit.    A little bit about the overview, individual, self‑paced, you can read all of these.    Very similar in some of these other things.

If you have seen the curriculum, it is sort of animated and they try to make it entertaining.    But it has that same feel pretty much throughout the whole thing.    We're going to offer three versions which is different than the curriculum now.    You have to take both OAE and ABR but with this you can take OAE and ABR and the combined course. 508 compliance is about electronic accessibility.    Accessibility to websites and there was a legislation that was passed in 1973 around this for federal programs.    We are going to be including that in this.    We will have pre‑ and posttest, post self‑assessment, all of that is being ‑‑ about being able to look at data and before they took the course and after they took the course for outcomes.    Certificate of completion CEU for us we will be offering lots of resources as you can see and really have a nice focus on CMV which you will hear about in a moment.    Here is the content overview of the new course.    I will skip this one for now and I will come back in a moment because I will share some of the content with you.

It has five main sections.    Again, introducing the participant to newborn hearing screening, getting prepared on how to screen check your equipment, infection control, making sure you are in a quiet environment.    All of those things that are critical for quality screening.    Section three, screening for OAEs and ABR, hands‑on videos in a midwifery practice that we are going to have as part of this in my most important section is five and we have a great communication with family section that we went from scripts to talking points because we just think it is easier for a person, a screener, to just look at these talking points and get the gist of it instead of having to memorize a script.    We went in a little bit different direction with that.    Getting back to the prescreening I am going to show you what we did was we created a section.

This is the very first section and it is really protocols.    The meat and potatoes of screening.    It is policies and procedures.    If I am a program manager or I am a midwife that has my own practice or I am in a doctor's office and implement in this, I need to know what I need to know.    Important for me to implement in whatever I am doing ‑‑ I will scroll through this section.    It will be different and it will provide this kind of very strong information about best practices and considerations.

What I'm trying to show you is from the very beginning, this is the actual content.    We introduce a state EHDI program.    We want them to connect with their EHDI program and know what the screening protocols are and know whether there is equipment that is being loaned, so all of this is really huge.    And to also look at the JCIH and then I will scroll through a few more things we go through audiology oversight, the importance of having an audiologist as part of whatever you are doing as a resource.    We talk about babies born with risk factors and how important it is to document this and to know which babies you should not be screening so we try to include that and we introduce congenital CMV and we talk about knowing whether you are providing this in whatever setting you are in and making sure you are connecting families who don't pass the initial screen to the next step, to the CMV screening if it is being provided.    We do some education on that.    We talk about screening methods, we talk about the timing of screening.

These are all really important things that need to be known for this type of screening environment.    I'm going to move along but I just wanted you to see how we are sort of providing this information.

I just went through this, but we do also have, we talk about the importance of documentation and reporting and minimizing loss to follow‑up.    This will be provided in what is called a rise course and it is more didactic and not animated.    Whoever it is that is taking the course can go through it slide by slide.    Like I said, communication with parents and families, talking points, English and Spanish, incorporating recommendations for CMV.    Handouts with developmental milestones, which will also be provided.

So where are we?    Our content completed.    We have finished videotaping and now we are in the process of the e‑learning piece and that will take about six months.    I would say seven months by the time it is done.    Then we will put it on the NCHAM website and we will release it.    We are very excited about this.    Stacy, do you have anything that I missed that you would like to add?

STACY JORDAN:    My other role besides working on awesome projects with Randi is I am an audiologist with the (Indiscernible) EHDI program so from a EHDI perspective, similar to the newborn hearing screening training curriculum for our hospitals, having something that is standardized that will exist if my position changes, because I train everybody now, but in our structures we are looking for sustainability and consistency of training.    As Randi mentioned, messaging.

That can continue to keep going even if our staff and capacity to be able to individually support these providers goes away.    As a EHDI staffer, it gives me an amazing tool for my toolbox to reduce the workload on myself to be individually training.    I have been a so many presentations in the last two days about staff turnover and new people and changes, so it is just great to have something that you can revisit, very similar to the hospital‑based.    Is there anyone in the room that has not heard of the curriculum at all?    The hospital‑based curriculum or not seen it?    I think I spoke too quickly.    It is hard to keep track of time.    Crazy.

>>: I don't have a question but I want to thank you for updating the hospital‑based program because it desperately needed it and I use it for all of my newborn hearing screeners that I train.    I make them go through the program and get their certificates.    I still do all of my training but it just helps them understand why we're doing it and have something to refer back to, but the other one was so old, so thank you.

RANDI WINSTON-GERSON:    Of course.    We are excited to have updated work and we will have three versions if we will split it up to ABR, OAE, and the combined course so that is coming in the near future.    Any other questions?    You guys got done early.    We have a few minutes to network out there.    Karen?

>>: (Off mic)

>>: You may want to mention some updates we have done since COVID, like the little cards that we have, frequently asked questions, that is probably still going to be in addition with a midwife's.    You will have those frequently asked questions.

RANDI WINSTON-GERSON:    Yes, the resources will be similar to what we have in the current curriculum but there will be frequently asked questions for screeners when parents ask questions.    As an added benefit I did do this with midwives a number of years back before we made the changes to make it a little simpler.

>>: I think the newer version will be significantly better because it was boring to some of the nurses because some of the nurses were midwives and others did not want to hear all the information.    It doesn't teach them on specific equipment, but it gives them all the understanding, and what is so great about this program is it is the only game in town.    It is a consistent message all across the US now and in other countries and am so excited because in Texas we have approximately 400,000 births per year.

[Laughter]

>>: Part of those are midwives and having something like this will make it so much easier to capture those kiddos.

RANDI WINSTON-GERSON:    Absolutely.    Yes, of course.

STACY JORDAN:    Just to piggyback on what Karen was mentioning, a lot of the resources you can see right now with the hospital‑based and we have done some updates for the community provider based versions, but one of the pieces I wanted to mention is there is that milestone piece and the results.    They are in writing so that the midwife or the pediatrician or the nurse in these outpatient settings in the community can make sure as we all know we want families to leave with their results verbally understanding it also in writing so they can take it with them.    There will be many community partner settings where the screening is being done is not necessarily their medical home where they might need to go back and say we went and had this hearing screening and this is what happened and it will have some information of the outcome and suggested next steps.

>>: Thank you.

RANDI WINSTON-GERSON:    We expect this course to be about 1.5 hours.    The current course is three hours from start to finish with all the adult learning activities that we are going to be providing to reinforce messaging, and also all of the little posttests after each section to reinforce all they learned in the previous section.    Anything else?    We still have five minutes.    Okay.    Any EHDI coordinators in here?    Where are you from?    Oklahoma?    Okay.    Louisiana.    South Dakota.    Yes, okay.    Are you using it in your program throughout the state?    That's great.    No, you are not.

Thank you so much everybody.    We appreciate you being here.    Thank you.

>>: Are you guys ready to start?    Captions working?    Great.    Okay, hello.    Welcome to this presentation.    I know today is the last day of the conference and it is getting towards the end of everything.    We just had our cookies, getting a little bit full and tired, so I appreciate everyone being here today and I'm excited to talk about the IFSP and my name is Sarah Honigfeld.    I am the national director for the early intervention center.    The national deaf education center.    I'm also the program director for the early intervention study of the graduate program at (Indiscernible) University.    We have some of the alumni here in the audience today.    Now I will turn it over to Chris who will introduce herself and start us off for this presentation.

>>: Hello everyone.    I am Chris, and I married a Greek person so my name is (Indiscernible) with NAD education policy Council National Association for the deaf and also hearing so I have two kids, one who is deaf and one who is hearing.    For the rest of the presentation today I will be switching to spoken English and I will be using an interpreter and our presenter, Sarah, will continue American sign language and the interpreter will come up right now.    Okay, our agenda for today, we will have fast and furious 25 minutes.    We have introduced ourselves and we will go over our learning objectives and the bulk of our discussion will be about the parts of IFSP, individual family services plan, and special considerations for Deaf and hard of hearing children.    When we use the word deaf throughout the presentation we are using it inclusively to mean deaf, deaf blind, deaf disabled, and hard of hearing kiddos, so all of those under the big umbrella.

We will leave you with some resources that given time I am not sure that we will have time to discuss in depth, but we will give you a little bit so you can keep looking if you want more information.

SARAH HONIGFELD:    So when we leave today in 23 minutes, we want you to walk away with these three learning objectives if you don't already have them under your belt.    We will talk about the parts of IFSP, special considerations in the IFSP for deaf children, and then the resources to think about whether you are a parent, whether you are an EI professional or both, to consider when you are developing IFSPs for deaf kiddos.

So IFSP, Individual Family Services Plan.    Most folks at this conference are familiar with broadly the IFSP, so the IFSP is a legal document.    Not to jump to the very end, but if you are a family, don't sign it unless you're comfortable with that because it is a legal document and it is the guide for the services that the infant and toddler will receive throughout early intervention, so whether that is in ASL specialist, speech therapy, audiology, physical therapy, OT, when they are going to receive it, how they are going to receive it, who they are going to receive it from, all those are going to be in the IFSP.

Every six months it is going to be reviewed and it is a document of that child's progress during the early intervention, during intervention.    So throughout we want families to be informed about the kinds of things that they are expecting for their child, what they are seen, how they are seeing them reach those goals, seeing additional support.

We want it to be family centered and strength ‑based, so what does the child need to be a full contributing member of the family and in a strength ‑based frame, what can we build on that the child is doing now and where we want them to go.    We're talking about an IFSP, we are talking about a whole child approach, so we are focused on deaf kiddos, it is a whole child, not only language and communication, usually important, but other things.    Gross, fine motor, social emotional, all that stuff that we need for healthy development in infants and toddlers.

And with that I will pass it off to Sarah.

SARAH HONIGFELD:    So she just gave you the brief points on what the IFSP is, and now we will go over the different parts.    I will explain some of the parts and what special considerations to include in the IFSP when we are working with deaf children.    I want to upsize again that deaf includes hard of hearing, deaf blind, deaf and disabled.    And also special considerations.    When you open the book the first page is the family page and it has all the information about the family, what their everyday routine looks like, and (Indiscernible) working with deaf child.    We should be thinking about the child's language environment.    What kind of environment there in every day.    Are they in a spoken language, spoken language, sign language, captions, ASL, Spanish, we want to recognize their everyday environment and with that language environment is like and include that on the IFSP.

We want to talk with the family and see what their previous experience was working with deaf people and if they have met the deaf person or when I go and maybe I am the first deaf person they have ever met which is fine, we just want to document that on the IFSP.    That info will help give us an idea and understanding of where the family is in their experience at that time and how involved they are in the Deaf community in their understanding of deaf culture.    Maybe they are already familiar with the culture or this is something that is new to them and I want to keep that in mind.

I also want to document that I make sure we get working on that right away.    We also want to have a conversation about audio access, what level they are at, because sometimes we are not sure and it's something we talk about later, but we need to set goals at that time.    Services.    We want the goals and services to match that child.

We want to have a clear understanding of what the family is like and what their understanding is of their child's level.    Do they have a cochlear implant, hearing aids, maybe right now they don't have that and maybe in the future the family wants to get a hearing aid and that is something we need to document because it will lead to future discussions and be able to get more information about their understanding about the child's hearing level and maybe the family does not understand at the time and we want notes to provide services that the family might need in the future.

Next slide.    So after the family page there is the assessment report.    The IFSP we have eligibility and eligibility assessment, speech language assessment, evaluations, movement assessments, we want to be able to look at all of the developmental domains and have a baseline for that child.

Now when we work with deaf and hard of hearing children we have some goals want to put in there in the assessment and evaluation page.    We want to keep in mind and be mindful of separating languages.    From zero to three ‑‑ for the national organization, do you guys know what the organization is from zero to three, nationwide organization?    Not only for deaf but for all children.    They have recommendations when you're working with families that are bilingual or multilingual, you should have a separation of languages and assess each language separately.

That is because each language has their own syntax.    Their own milestones.    And at different expectations one children at that age will arrive at those different milestones.    It is impossible to do that the same for all of the languages, sign language's, spoken like which, spoken English versus spoken Spanish, they are different and need to be separated.    Some of you are saying we do not have enough providers for that.    This is the goal.    This is what we are aiming for.    A good, high‑quality IFSP.

Next when we use the assessment we often, because of the evidence‑based tools, because we are missing some of the evidence‑based tools that we need right now in our field, often times what happens is we will take an assessment from hearing children and try to apply that to the deaf children.    I'm not sure if that is always the best approach.    Sometimes we are just stuck in that is the option we have.

If we use a tool that is not designed for deaf children we need to document that as well, to recognize the limitations of that assessment.    We want to have and make sure the assessment that we document the assessment may be missing some of the information that is important for the report and recognize that and it is important that we try to use appropriate normed assessments.

We recognize many families have different cultures online which is, different line which is at home, and the assessment is really based on our white, Western privileged norms.    So some of the expectations that we set up are very different than what the child's norms may be in their culture.    Maybe their culture really cherishes being close and ‑‑ walking impacted may be impacted because the families culture is much closer and they may not have missed that milestone but were misunderstanding through the cultural lens.

We have to make sure whatever assessments that we give, that we don't overlook the important language and cultural aspects that may happen at home.    I'm trying to be as fast as possible.    Now that the assessments are done, now we are ready to talk about the goals and what we want for the child and the family to successfully achieve, so with deaf and hard of hearing children, again, the goals should ‑‑ the child, the goals ‑‑ would not just say the child should use online which is, who want to separate the languages for the same reason.

They'll have different milestones, different expectations, different skills included with different like which is, and we want to monitor each language development separately.    They have separate goals for each language.    Maybe the child is been exposed sign language and they should have sign language goals.    If they have spoken language should have spoken line which goals.    If they have been exposed to both English and Spanish, how many goals should they have?

Two.    One for English and one for Spanish.    Next in this field we are passionate about our deaf and hard of hearing children.    So often times we get incredibly focused on deafness and language and we forget to step back and look at the child as a whole child.    Maybe they have other needs that we need to address.    Maybe their family has needs we need to address.

Maybe the family's basic needs, their nutrition, housing, emotional support, or maybe the child has physical motor needs or cognitive needs, so we need to be mindful to step back and look to see what other areas we might need to address without family.    We cannot just look at only sign language and speaking and cochlear implants.    We need to step back and address everything.    I already addressed cultural identity and how that can happen in families homes versus we need to be able to include all of that in the IFSP.

We want to really talk to the family and figure out what is important to the family and anything in their heritage that they want passed down we need to include in the IFSP because that is important.    I talked about hearing levels and I want to be very transparent about that with the family to make sure we have appropriate goals were hearing levels.    At the JCIH we have recommendations for services for deaf and hard of hearing children.    The goals should refer them to that based on hearing level.    If they don't match what the child can successfully do it would be incredibly hard to progress with the IFSP.    We want to make sure the goals are appropriate.

I mentioned family services and supports.    We can write an IFSP that matches the goals.    If they need access to information about how to install car seat, we can include that in the IFSP as a goal.    That can be part of the family centered based services.    It is an IDEA as a law.    Very fast.    So the goals should be specific and measurable.    The child will be able to express what their wants and needs are.

What exactly does that mean?    To who?    For what?    How many words would they be encouraged to use?    And needs to be a more specific goal.    We expect when we say goal, we need to be able to measure that goal.    So again, once we have the goals, we have a service grid.    All of the services that child will receive we set up integrated.    They will receive them from, where, at school, at home, everything is listed in a grid along with the frequency.    For deaf and hard of hearing children, some of the things we include in the grid is we want to emphasize if they are looking into getting a cochlear implant we want to put that on there as well.    And we want to identify the different programs that are available like deaf mentors.

So some states have deaf mentor programs and we want to put that on the IFSP, on the grid, so a deaf mentor could go to the family's home.    How often the child may interact with the deaf mentor.    We want to put all of that on the services grid.    If an agency says we don't provide that service, it is no problem, we can make sure to put that information down so we know how to support the family in finding that service elsewhere.

Again, this is a legal federal document.    It is an agreement between us, the team, and family.    Anything we put on there for deaf hard of hearing adults being involved, we need to make sure we also refer families to events and put that on the IFSP.    We want to include all the different ways that adults, deaf adults can be included in the IFSP.    Some of the goals, remember I emphasized separation of languages, same thing with the services grid.

If we have an ASL goal we need to have ASL services.    If we have spoken language goal, we should have a spoken language service school.    It's not all in one person that will provide all the services.    Nobody would be qualified to provide all of the services so everything is separated into separate service grades.    Last, the natural environment.

IDEA talks about the natural environment as the child in their everyday, ongoing life.    Same with children without disabilities.    IDEA also identifies the federal government released a memo re‑ explaining the natural environment for hard of hearing children and it includes peer environments.    Maybe that is not in their everyday routine because they are deaf and the deaf population is very small, so it is harder to find other deaf children that they see on a daily basis.

So IDEA, the federal government, did allow an additional service for us to consider the appropriate natural environment for hearing children but also allowed for playgroups and sign language groups, and playgroups with deaf hard of hearing children is allowed to be put on the IFSP so do not let your teams tell you you can't put it on there.    You can.    The law says it is okay.

We will give Sarah's hands a break.    She is signing so fast.    I split up the deck.    One thing I want to emphasize on ASL spoken language services, sign support and spoken language services are often not offered in the same way.    When my son was a baby and we identified his as deaf and someone came over for sign support and she followed us through our bedtime routine showing me signs for bath.

This is completely not helpful at all, and also not equal to the speech therapy services that was offered, and I am a Type A lawyer mom so we kind of stopped that and I live in D.C. so we had a lot of things going for us but a lot of times families will know that.    That the sign support is not the same thing as the services you are getting for spoken language so specifically asking for ASL services at the same level that you are getting in a speech, like families don't know what they don't know.

And then really, deaf adults are required to be involved by law, often it does not happen.    Sometimes maybe it can be easy to overlook how much hearing parents don't know.    I remember when my son was identified as deaf, he was seven months old, but he was the same person.    I just had new information about him.    How do I read to him?    Because hearing people, you put the baby on your lap, the book is in the front, and you read.    Well, this isn't going to work.    So I put the baby here, I put the book here, I need a third hand.    And I need to learn how to figure out how to sign this.

It was so much easier than trying to figure out on my own.    I had a deaf mentor came over and she is a dear friend now and she laughed and took my son a put him down and there was so much that hearing parents who don't know what we are getting into will learn from deaf adults being meaningfully involved.    All sorts of organizations in terms of ‑‑ a lot of hearing parent involvement and there is only so much hearing parents are going to learn ‑‑ all of our experiences can be valuable, blah blah blah, but for deaf parents it is not that I'm going to do the exact same thing that you deaf family are doing with your deaf baby.

That is going to be a competely different experience for me to learn from that and try to figure out okay, I need to grow a third arm and then I can reach my son in this natural environment.    Okay, now back to Sarah for the fast and furious.

SARAH HONIGFELD:    Now we're going to talk about goals and setting up services for the child.    Maybe they have already been receiving services which would be fantastic and then they hit two so now it's time to transition and start talking about Part C services.    What happens and what we do for deaf hard of hearing children next?    We want to make sure we informed the families of their ability to access advocacy services, and we also have at the state level what is available as well as the regional level what services are available.    If they have a School for the Deaf, maybe they go to a commission for the deaf and hard of hearing in the state, or private agency.    It would vary in the different ways they can access advocacy services and often the families have no ideas ‑‑ idea and we inform them to know that they can request advocacy services and come and explain to them what Part B looks like in the process and the transition process.

There is a box on the IFSP for transition services.    You can add it right there.    Please contact your advocacy services and you can put it right on the IFSP for the family so they can remember that they have to call and let them know they are transitioning soon.    I also want to talk about Part B services and talk about the opportunity when there is option apply to the entire IFSP.    The language in terms that we use as applications provides an opportunity, placement opportunities and also also opportunities for services.    Not that that is all you're getting, but something you have to keep in mind.    So something else to put on the IFSP is encouraging the families to network, to introduce them to other families who have recently gone through the transition process with a deaf hard of hearing child and introduce them to other families that have been receiving other services and that way they can communicate to other families what their experience was like.    Providing networking experiences for the families.    Next slide.    Two minutes and I'm done.

Before we get to the resources, one thing also to emphasize with transitioning, families often don't know that just because the kid gets an IFSP does not mean they automatically qualify under the IDEA for an IEP.    The eligibility requirements are different.    Sometimes especially for hard of hearing kiddos, kiddos with unilateral hearing levels, kids who are academically hitting the benchmarks, families need to make sure they know they are documenting all the services they are getting on the IFSP so they can get them in the IEP but it is not guaranteed.    Or not automatic is a better word.

We will leave you with a list of resources and I think that is what we will leave you with.    Make sure families don't sign it until they are satisfied with it.    And here's our contact information and thank you very much.

[Laughter]

>>: Thank you and I appreciate it.

ALEX MESTRES: Good afternoon, everybody.    I would like to welcome you to the last presentation of the day.    I hope you have had a wonderful experience.    EHDI.    My name is Alex Mestres and you are here ‑‑ self advocacy success and early intervention and beyond.    Unfortunately, my co‑ presenter Danielle is not with us but fortunately for her she is very pregnant and was concerned about the Colorado weather, and traveling during pregnancy, so I am here myself.

I am a teacher of the deaf and hard of hearing and I work across various districts in Miami‑Dade County, and I also work for the children's hearing program where I am the educational specialist for our hearing program which covers hearing aids, cochlear implants, and my disclosures are with ‑‑ financial aid committee.    I am hoping if you are here today you are ready to increase your knowledge a little bit about self advocacy in early childhood.    Some ideas about how to approach it and think about how to motivate these kids to do it.

Let's get started.    Self advocacy.    What is it?    I think everybody pretty much as an idea what it is, but the official definition is that it is an ability to understand and effectively communicate what you need.    Communicate that to others.    It could be a difficult task.    Sometimes we say well, what is language versus self advocacy?    I don't think it is really a versus.    I think it is interdependent.    Languages are the ability to communicate where self advocacy is the knowledge of how to communicate those wants and needs.

It is very interconnected, but I suspect if you are in early intervention whether you an audiologist, educator or parent, you know that.    What you probably know about self advocacy it is not a straight path.    It is not something we can teach starting at birth and go through adulthood in a straight line, and have success.    There is lots of twists and turns in itself advocacy.    Asking for help, communicating what is helpful to you, enriching language specific to that.

Defining success with self advocacy.    Identifying challenging situations, and determining options in response to challenges.    That can look different at every stage of development.    So it is something that we have to start from a very early age.    Now we all know that self advocacy has its benefits.    Just to put some research behind it, Scott Sheldon and Hawthorne said that self advocacy skills in anybody can increase quality of life.    You feel better when you can advocate for what you need.

You have a sense of self and you build confidence and it places the language responsibility on the person, or in this case, the child.    I believe that it is a confidence builder.    To feel like you can speak up for yourself at every age bills that self‑confidence that children with hearing loss so desperately need.    We know so much about it that we even in some states embed it into our guidelines and our standards.

Starting at a very early age, preschool even.    Kindergarten, first grade, we are writing goals centered on self advocacy and making sure that students have the language of self advocacy to ensure as they go forward at school that they have that support.    It is foundational.    In fact, self advocacy can be defined as an ongoing process as you see in this diagram.

It is something that goes on and on and on, but for us where does it start?    It starts with that first box.    Self awareness.    What does that mean?    It means understanding yourself.    You have to know who you are and what you need.    You have to have your personal experiences.    What does it mean to you to be deaf or hard of hearing?    What does that mean at five or at three?    What does that mean at two?

You need to know your strengths and weaknesses and it sounds like a lot to ask a toddler, what are you good at?    What is hard for you?    That is challenging.    You have to know how to communicate best, what is your best way of communication.    How will you get what you want to say out and have it so people understand what you need?

Having a basic knowledge of technology and how that works for you, if you have it.    Or if you have it, or if you don't have it.    Those are all important things when you're trying to figure it all out.    That means we have to take the language in the skill of self advocacy and put it together.    We talked therapeutically or educationally we might say here's your self advocacy goal and here's our language goal.

Now we will teach that structure.    We need to teach structure, language structure, we know that.    Then we have to create opportunities.    They can be opportunities to succeed.    They can be set up to fail so you can turn around and succeed, but we create those opportunities and then will we hope is what these children, even at the very early age are taking in, is a way to implement those strategies.

For example, we might say to a toddler, we want them to ask for what they want or what they need.    That is the advocacy goal, but on the flip side the language goal might be how we do that in producing a vocalization or sign or single word.    Then we go about the job of teaching that structure, and then creating those opportunities that support that sign, that vocalization, that language.

Then we let it loose in the classroom or in the educational setting or at home, and hope that those strategies become habits and those habits build a foundation that move them forward to maybe the preschool age where we move that up and say we want these children to request clarification.    How hard is it to say I did not hear you?    I don't quite understand.    We want them to have that.    We have to figure out away at their level, the preschool level, that there language will allow them to do that.

It might be a three word sentence with pronouns.    He needs, she needs, I need.    That is the way to support the language of it.    Again, it is a taught skill.    It is something that brings language and self advocacy together to make it interconnected.    Then we create an opportunity, and again, hope that those opportunities lead to strategies that become lifelong learning and self advocacy.

Actually the ultimate goal in all of this is to help kids navigate their hearing environment.    Navigate their environment through their hearing loss.    Their hearing loss is a reality.    It is a reality.    It is not something that we set out to change.    It is something that we help them through, and I loved the presenter the first day, the keynote, which she talked about this is our normal.

This is our reality.    It may look different than your reality and that is okay.    But we have to teach children to navigate their reality.    Anytime we teach something or we expect something, do you know what the key to it is?    At least from our perspective?    Motivation.    Think about what motivates you to do something.    Are there any runners in the crowd?    God bless you.    I am not a runner.

I tried it.    I am under motivated.    I promise you.    I tried walk and run into you walk motivated.    How many of you have finished a marathon or one half?    Holy cow, that is too many.    I feel this big right now.    But if you did it, how did you feel at the end?    You felt it was something you could be proud of because you were motivated to do that.    Self‑determination theory gives us an inkling or a peek into what motivation really is.

When we think about motivation, we have three basic psychological needs.    Every human being, regardless of how old, we need autonomy, competence, and relatedness.    They are all underlying growth and development.    That is what motivation is.    When you think about it, when you think about it in terms of self advocacy, think about relatedness.    The need of connectedness or belonging with others or even the challenge or the problem.

Is this issue important to me as it relates to this situation?    Am I motivated to be related to this issue?    Competency, the experience or mastery of one's activity.    You guys that run know.    You master this activity.    We have to expect the same thing of children and that is why that interconnectedness with the language is so important because what we want to ask is do I understand this challenge enough to address it?

Autonomy.    This is the hardest one.    The feeling one has a choice and willingness to endorse one's behavior.    What are my choices in this situation?    That starts very young.    Toddlers exercise their right to choice all the time, don't they?    Don't they?    Regardless of their language, they exercise their ability to choose or not choose or whatever it may be.

That is an important part of this when we look at self advocacy and motivating deaf and hard of hearing children to use it.    This is about choice, not control.    That is where the road to success lies.    When we get that strategy and that language skill, we put them together.    We have to motivate them to use it in the classroom, however the purveyors of self‑determination theory recognize, and I would like to point out this is their word not mine, that when a child has a disability we often feel the need to intrinsically control their motivation.

The more disabled we perceive a child to be, the more we tend to control the situation.    How many people have heard well, if this child will just do this, I want them to do it exactly this way, but this way, your way, takes those other things off the table.    So does controlling the narrative truly set students and children up for success?    Arguably, yes and no.    Yes, language structure.    Yes, we need to teach them the language of self advocacy, but we need to give them a chance to motivate themselves for success and we need to coach that more than teach that.

And that is an important difference.    So when you think about self advocacy, some of the general suggestions we might have is to give children some control over decision‑making.    How many audiologists say what color hearing aids do you want?    What color background cochlear implant ‑‑ there's 15 different colors.    I saw purple.    She will be so excited.    Choices.    It seems simple.    Choices between this and that.    We do it all the time.

We need to give some children control in the decisions they are making, even at the youngest age.    Does that take us out of the equation?    Absolutely not.    This is guiding as opposed to directing.    Give children a chance to solve their own problems before stepping in.    This is challenging especially for parents.    We do not want children to fail.    I'm not suggesting that we let children fail.    I'm suggesting that we let them stumble and guide them in picking themselves up.

That will motivate them in the future to become self advocates for what they need and what they want.    Praise children when they ask for help and also asking for help.    Practice asking for help.    Let them practice asking you for help.    It is okay.    Even when they may not need it, even when you know they can do it, it doesn't matter.    It is practice that is motivating and it gives that level of competence that is needed and gives that level of relatedness and gives that level of autonomy even if they ask for help 1000 times.

How many of you have heard are we there yet?    Are we there yet?    It is the same idea.    That practice and success is what will build that motivation.    Have ongoing conversations about strengths and challenges.    There are real life challenges to having hearing loss.    Does everybody agree?    Regardless of what your modality of communication is?    There are challenges, and the more we embrace those challenges and show children what the strengths are within them and the strings they have to meet them, we build resiliency and rebuild their motivation to advocate for what they need.

When children are faced with those challenges even when they are little, ask what they think they need.    Not what you think they need.    You may know.    Sometimes you look at a situation and say I know what they need, but do they know what they need?    Do they have a way to express it to you?    I often tell children that you do not speak mom.    There is a way to speak mom.    Speaking mom is like I'm going to do it because I want to.    That is not speaking mom.

We want to give that language, that celebrates the idea to explain what is going on even at the youngest of ages.    My ears aren't working.    My battery died.    Those types of things.    Give chance in the real world to use their own voice and I am saying literal voice.    Figurative, not literal.    Given that opportunity to do them in a way that fits their personality.    That is the relevance.    That is their competency and autonomy.

If you are in this room and you are an early interventionist, you are a teachers coach.    So my advice and our advice in all of this when you are thinking about motivating children to have self advocacy skills, start early.    This cannot start early enough.    Target the language of self advocacy.    Celebrate it.    Utilize daily routines as opportunities to practice.

That is where the competency comes in.    That is where they learn how to do it.    Give them that environment where they know what the expectations are and have that established responsibility and they know.    They are able to do it because they feel competent and related in the environment and they have choices.    They know what choices they have.    Start to pass the baton to them.

More and more, move the narrative to them, not you.    And provide a variety of experiences to express their needs.    Volunteering, appearing with a mentor, whatever it looks like in your arena.    And a big thing when you target the language of self advocacy, there is a lot of power in do you need help.    There is even more power in the words of how can I help you.

We know when kids need help.    But giving them the voice to say how we can help them is very important in the world of self advocacy.    And you are also coaching for that communication breakdown.    We know they are going to happen.    That is the reality.    Communication breakdown happens in every setting.    We want to support his early interventionists, we want to support that communication that you need help.    Whatever that looks like.    An eye glance, downward look, what is it, I do not understand, whatever that language is you want to support it and then you might want to flip it around to say what is helpful.    I need help with, did you need help?    You need help with what?    I'm sorry?    What was that?    Can you repeat?    Give them a chance to take the time to express themselves and enrich those language and repair strategies.

Start with clarify.    I heard you say this is what you need.    That will help in building that motivation to become their own self advocate.    And if you are working with parents because a lot of us do, coach parents to be coaches.    It is tough enough to be a parent but it is very hard to be a coach.    As a parent we want to rush in and help.    So encourage parents to ask specific questions that are centered around self advocacy.    They want to manage those communication breakdowns, as well.    Help their child communicate their needs and understand their technology.

Provide time.    Give them time to answer.    Give them space to figure out what they want to say and how they want to say it.    Give them room for mistakes.    Don't rush in.    Provide choices, autonomy.    This is a big one.    We'll want choices in life.    Consider their needs.    Encourage parents to consider their needs and consider personality.    There are some children that you know are very gregarious and we say wow, that child is really outgoing, and then there are some children that are shy.

We need to draw them both into the world of self advocacy, so you have to consider that when you approach them and that comes from coaching, not teaching, and provide opportunities.    Real‑world opportunities can provide the best motivation to be a self advocate.    What do you do when you are in the classroom in that early childhood setting, in that pre‑k class, that is not quiet and you don't understand what is going on?

Or if you are not sure of the signs that are being used.    What do you do?    How do you navigate?    I don't hear people say it anymore too much, it is that teachable moment.    Find that teachable moment and turn it into a coachable moment.    That is what we need to work with parents to do.    Some of us as teachers do that inherently.    I even think our audiology friends do that pathologists, as well.

We need to coach parents to be on the same page.    Become their cheerleader and their guide.    But don't do it for them.    And there is resources out there.    Like anything, we have resources.    They are out there and you are welcome to download my presentation and with all of them, links.    There's multiple resources in multiple states, multiple states use expanded core curriculums and those are great resources.    Lynn Price has great resources.    There's a bunch of different resources coming from different agencies that look at it in all sorts of different ways.    Not just talking about from the language point of view but talking about from the self advocacy point of view.

Self advocacy is important regardless of our modality.    Even more resources.    There are some great organizations out there that take the time to really make sure that we as early interventionists, audiologists, and speech pathologists, and parents are supported in creating good self advocates.    Now my advice going into all of this is teach the language of self advocacy.    It is important.

More important.    Motivate children to do that.    Coach and guide them, don't direct and dictate.    Kids will know when you're doing it.    That's okay.    Honestly, for parents there are some things we have to dictate.    But you can find choices in that dictation that are motivating for children.    Make them feel like they have some say.    Engage in dialogue, not just conversation.    Dialogue and conversation are two very different things.

Dialogue means I value what you say and you value what I say.    And we are both listening.    Ask more, suggest some, tell less.    You want to motivate children even at an early age to use self advocacy and the strategies that they are learning.    Ask more questions, offer some suggestions, and tell less.    And I always say it remember, one of the things I tell my students is I don't have hearing loss.    That is a fact of life.

So I can't tell you what it is like for you, but you tell me what it is like for you and I can help you from there and it can make some suggestions based on some things I know but in the end I will not tell you what to do.    I'm going to help you find the right direction.    Embrace creativity.    This is a big one.    Don't cut from the cookie.    How many people from IEPs or IFSPs use drop‑down menus?    Valuable?    Yes.    However, we are not all the same being.    We don't all come from the same cookie‑cutter, so it is very important, both IFSPs and IEPs start with the word individual and we have to remember that.

Embrace a creative way to look at self advocacy.    I promise you will be building a better foundation for those children than cutting from what we think we know.    And follow their lead.    Don't drive.    Let them lead and show you what they need because for every child that is going to look different and if you want to motivate them to build a foundation in self advocacy through language, you have to let them lead.    With that being said, I will take any questions.    Yes, ma'am?    There is a microphone coming.

>>: Hello, this is great information and I am a deaf teacher and I always think advocacy starts at a very young age, even at the age of two to show them pictures so they can use that to show where they want to go, they have a lot to learn from their experiences and also in the curriculum we use there are different topics.    This week, what do we want to learn or study.    Maybe we are talking about different things and we pick different resources like books and I see they are motivated to learn based on their experiences.

ALEX MESTRES:    And that is powerful because it is defined as communication, language.    The motivation comes no matter what it is.    Is it pictures, is it words, whatever.    I love that you say you ask them what do you want to learn?    That is an amazing and powerful thing in the classroom to say what you want to learn.    It gives them so much buy‑in to be interested in learning the language that they need to have to learn those skills.    Other questions?    All right.    These are my references and my resources.    At the beginning of the slide and on the app, both Danielle's and my e‑mail are there.    I'm happy to answer any further questions and give you the resources on the self‑determination theory although they are in the handout for the presentation, but thank you for coming at the end of the day.    I hope you all have safe travels home wherever you came from.