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EHDI 2019

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IT TAKES A TEAM

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>> Hello. Hello. I think we're ready to get started. My name is Michelle, and I'm here to introduce our second breakout session at the moment. Our title is an interdisciplinary approaches. Let me get this right. To improving the outcomes for deaf and hard‑of‑hearing children. Please do notice you've got evaluations on your seat. There's actually several more evaluations at the front of the room, and if you need extra forms, we have some. If anyone hasn't received theirs yet, please see me for that. Thank you very much.

>> Good morning. My name is Sarah Stone, and I am the director of the newborn bob hearing screening program in Massachusetts.

>> Hi. And I'm Jennifer Fleming, I'm a proud parent of two, and also my youngest son is deaf and I'm a special projects coordinator for a program.

>> All right. So we don't have any financial relationships to disclose. And these are our learning objectives, and it looks like our slide headings have been cut off, but we'll work with it. So the universal newborn screening program in Massachusetts, our law was passed in 1998.

There are three major components of it. The first is screening is done at all hospital prior to discharge; that children are sent for a diagnostic program at a center that is approved by the Department of Public health; and the third element is that an advisory committee was formed. And the advisory committee is specified as to who the members are. It does include parents and consumers. We have funding from HRSA, from CDC, and a small amount of funding from the state. We are a staff of six, which includes parents and consumers, two of our staff members are part time. And to give you an idea of how big our system is in Massachusetts, we may be a small state geographically, but we have a pretty large population. So we have 48 birth hospitals, and we require that there's an audiologist for every single one of those programs.

And there are 40 audiological diagnostic centers. All of those centers are approved by our program, and, in order to become one of our approved centers, they have a data agreement with us. So something that is not included in our law is the idea of consent from families at the diagnostic process. So there is no consent needed for families for us to receive information about screening, but we do need individual consent from families to receive information about diagnostics. So that presents some challenges within our system.

We also have 60 early intervention programs within our state, and we are very fortunate that all children who are deaf and hard‑of‑hearing eligible for EI within Massachusetts. So lots of folks to work with.

These are statistics that you're all probably very familiar with. 98% of babies are now being screened before leaving the hospital. Babies who are receiving hearing evaluation before three months has increased from 52% in 2005 to 76% in 2016. And between 2005 and 2014, over 45,000 deaf and hard‑of‑hearing infants born in the U.S. have been identified early.

However, the challenges. So 25 ‑‑ again, this is nationally, 25.4% of the babies are lost to follow‑up for diagnostics, and only 67.2% of children who are deaf and hard‑of‑hearing are enrolled in early intervention. Notice that that's not by the benchmarks of six months. That's just enrolled in early intervention.

In 2017, Christine Yoshinago published an article in pediatrics stating across participating states, only half to two‑thirds of identified children are meeting the guidelines of 1‑3‑6 and that much work needs to be done. She suggested a team approach that includes newborn screening personnel, audiologist, early interventionists, state‑based EHDI program that can monitor the system from screening to diagnosis to EI.

So Massachusetts, we were ‑‑ we've been working really hard at this for a very long time, and we were able to celebrate for our 2016 data a lost of follow‑up rate of 3.2% which is just a phenomenal benchmark for our program. But it takes a lot of work and there's a lot of different players within that system. So for the birth hospitals, which obviously is where it starts, we are relying on‑screeners to screen the baby and to report accurate information in to our ‑‑ in to the birth certificate, so we work with the birth hospitals and with vital records to get that information.

The screeners are making an appointment for the family prior to discharge. And then our staff is following up on that information with the families. And so we have a lost to follow‑up coordinator and an epidemiologist who are following those families through the process.

The lost to follow‑up coordinator is calling the families to make sure that they know about the appointment, you know, ensuring that the information is accurate, that they know where the appointment is, they can get there, they don't have any problems with their health insurance, they know the instruction s that may Bay bee needs to be tired and hungry and all of those things that you hate telling families who might have to drive two hours to get to an appointment. But we're reenforcing everything that the audiologists are saying.

The pediatricians are also enlisted for support. If a family misses an appointment or if they're eventually identified as being deaf and hard‑of‑hearing. And the audiologists are really critical piece within this because they have the families in front of them, they are able to report milled appoint some we can do additional follow‑up. They're able to report to us the results of those appointments. And if the family is identified as having a child who is deaf and hard‑of‑hearing, they are in the presence of that family and they can them make that referral to EI.

So we've brought folks together in different ways. We have diagnostic center meetings where we bring all of our audiologists together who are in leader ship capacity in each of those centers. We bring them together twice a year, and we also have a webinar each winter. We've established a relationship with early intervention. We are in the same bureau as EI. We have a separate data agreement to receive information from them.

They have specified a person at each of the 60 EI centers who is sort of the contact, if you will, for deaf and hard‑of‑hearing issues. So they might not be the service coordinator for that family, but they are the point person for the EI center.

Our advisory committee has 14 members and they approve all of our policy documents. And, as an outgrowth of this meeting actually, we started doing EHDI stakeholder meetings back home. So it wasn't a why do we need to come to Chicago to talk to these things, it was why don't we get together in Boston and have the same conversation. So we meet with our stakeholders a couple of times a year.

And for our HRSA grant we also start add learning committee this year which is a smaller project‑based team which is executing on state level needs, and what we're going to talk about is a project that came out of the learning community.

So we want to throw it out to you, what are other examples of way that is you have brought folks together within your state that has been effective? And we have a roaming mic as well.

>> Absolutely. Who would like to share? Anybody? Gosh. If anybody has any ‑‑

>> We ‑‑

>> Thank you.

>> Hi. I'm a parent from New York State, and our EHDI program does the learning communities as well, and they've done a great job of making sure that there's not only individual parents like myself represented but also they work with a, a parent to parent, so a parent run organization is there as well and just making sure that there's always a parent on the advisory group and I think they've done that across the board with all of their stakeholders, so there's always an audiologist, so very similar to what you guys are doing.

>> I love that. And how a parent is included is central. Love that.

>> And I'll add to, so just, within our learning communities, they are set up I guess sub committees almost so there's our largest hospitals that were involved that had a lot of follow‑up number, we're sort of targeting them. And so a parent, an audiologist and the hospital were paired like as a smaller team and also had like sub learning community meetings outside of the bigger quarterly meetings that we had.

>> That's great.

>> That is very cool.

>> Yeah.

>> Other ideas to share?

All right.

>> Okay.

>> So we're going to talk about family engagement, and you defined it just perfectly by saying we have a parent in the center of everything that we do, key, and then Dr. Swenson this morning really set this up in terms of defining what family engagement really looks like. And he said it's not to, it's not for, it's with. And that really ultimately is family engagement. It's having the family as a critical partner in the team. And why is family engagement important? It's important because the families that are engaged, their children do better. It is really that simple. This is a quote from marry Pat Moeller who talks about language delays and shows the correlation there. We also have something.

>> The Joint Committee on Infant Hearing that talks again about the team approach and how the families that are engaged with early intervention and with their state EHDI programs, they are doing better, that team approach, again, being critical.

So this kind of led us to developing a visual guide. So this is the project that came out of the learning community. We're going to talk about how it came to life, why it's important, describe what it is and how we can use it.

So the learning community that Sarah talked about, on ours, it's a smaller segment, interdisciplinary team, so we have a neonatologist, early intervention, the mass commission for the deaf and hard‑of‑hearing, specialty service providers, EHDI, of course, pediatrician, parents, audiology, it sounds really big, as I'm going through, but it's wonderful because there's so many different perspective that is come to the table. So the first project was, let's develop a roadmap, so something for families that kind of shows what the progression over time might look like for their families, what are the services and support that is are available? So we looked at the different tools that are out in existence and decided, let's give something a try. Let's try something on our own. So what we did was we came up with an individualized tree, if you will. So one family's journey of the different services that they received over time.

And then we used all of our different groups and stakeholders to expand that individual tree in to a tree that works for everyone, something that can be tailored made to each individual family that you're working with. So the learning community certainly was huge in terms of their contributions here, the EHDI stakeholders, the diagnostic audiologists, parents, Deaf and hard‑of‑hearing community members, and we came up with, here is our tree. So it is front and back, there's a lot of information, I'm going to walk you through the tree and how it is designed. So we're really going to start at the base of the tree and work our way up. And, of course, the base of the tree is our program, the universal newborn early screening program, because if you haven't identified the kids, you can't help these families.

So the way that I'll kind of walk through is there will be a definition on the top, so when you flip the tree, the page, you'll be able to see that definition. So this description is on top. And then this tucks a little bit about our program. Thank you. So you'll see it's on legal size paper, the tree, and then on the back, these are the descriptions. So those descriptions are going to be matched there.

So we've broken it in to different sections based on age. We're going to start off with the birth through three section. So you'll see these are the different leaves. We have early intervention, SLP, specialty service providers, teachers of the deaf, family sign language program and deaf hard‑of‑hearing program consult. So I'll talk a about a few of these leaves, I won't go through all the detail. So we talk about early intervention, and we all know how important early intervention is, but families don't necessarily know that. I talked recently to a family at a conference and she was talking to me about her daughter who was in middle school and who is struggling, and she was talking about her daughter's journey, and she said to me, she goes, well, we didn't do early intervention. And she started sobbing. And she is like, I just, she whispered, she's like, I just didn't know. And I can relate to that. You can't fix what you don't know, and that's one of the things that we really hope that this tree can do. Because we know that this is such a valuable gateway to services. So that was kind of sad. I'll bring a happier story the next one.

Specialty service providers are huge. These are the providers that we have that specialize in deaf and hard‑of‑hearing. They have expertise. And the beauty of this slide, I really like how we describe this to explain to families that you don't need to choose just one provider, and it's not a static decision, because things change with your children as they develop over time and what you need at three months of age might be very different, typically is pretty different, than at four years of age. So this kind of shows how you can have more than one specialty service provide but they work very closely with the early interventionists. And if you go to our website, which is really the goal, you'll be able to see the eight‑page document that walks you through. So it will give you that breadth and depth of information that you might be looking for.

Speech language pathologist, of course, a key member of the team. I talked to, this is kind of another extreme, recently, and she was talking about her ‑‑ excuse me, she has a nine month old child and she met another mom who had a SLP coming in to her house and doing services. She was so angry. She said to me, I didn't even know what a SLP was? That's where the tree comes in handy. This way, everyone know what is out there so you can make families decisions that work for your family.

So switching to the other side. This is kind of the health services area of our tree, and I won't walk you through the different leaves. We'll focus on a couple. Pediatrician, what an important role the pediatrician has in terms of their voice with this family, they're following through with the family, development, milestones, over time, and they have such a huge voice. But the pediatrician is often faced with a pretty big challenge in that they might have one, two children in their practice with hearing loss but yet they're expected to be the expert. So this can be something very valuable for them as well to know who is on the team, who are the different players, and make sure we're all working together to help that family.

It is funny, our pediatrician, my son is now, I think I mentioned he's 12, and I have a daughter who is 14, and still, he's the only child with hearing loss in her practice. So I think that speaks to. But she's unbelievable at referring, and that was one of the things. I didn't need her to be an expert at hearing loss, but I needed her to tell me to get to you, to all of the people in this room, who do know about hearing loss. And the more we can educate our pediatricians to find you, to know that you're there, and helping them help their patients, the better off I believe we'll be.

So ‑‑ distracting not having ‑‑ so this is the audiologist. So this talks about how we described it on the back and then gives some information that Sarah described about what to ex approximate expect when they go to the diagnostic audiology appointment and also if they have not identified where they're supposed to go, how to get there. So an ophthalmologist, and you might wonder, why is this on here? Well, of course there's a lot of syndromes that are related with hearing loss and vision loss, but as a family, I remember, why am I going to the eye doctor? Like what is going on here? So I think this could help in terms of compliance for families to know why they are being referred to different areas. And, again, important for that to happen.

So we're moving up the tree, over time. And you can see, it's a lot of leaves here. But it doesn't end after early intervention. And as you know, that transition from early intervention to school‑based services is a big deal for families to try to get their head around. And there's different, like, people that are coming in to the team to help make that work. So this kind of describes some of the different people that are going to be on their team as they get into school. And I'll pick out a bunch. Just to say like this is not Massachusetts specific. I think this really applies to a lot of different states there. Might be some subtleties in here, but, for the most part, I think it has broader appeal.

So we'll talk about, so this is the IEP504. So I remember or I was talking to a family and they were talking about the IEP versus the itching FS ‑‑ what? Thank you. And they were like, I don't know what's going on. They were all confused. But this, at least on this document, it puts everything together so that you can see one versus the other. Not that when your child is six months old you're interested in what a IEP is, but that is coming and it will help, hopefully, prepare the family to be less anxious about what is to come.

And the difference between an IEP and a 504 and the people that are advising you, this document is so important in terms of setting the stage for education all the way down the road. Huge, hugely important, in my opinion.

The educational audiologist has an unbelievable role in terms of what they can do to help make things work in the school setting for your deaf and hard‑of‑hearing children.

And I really like this quote from Kirsten Marconi‑Hutkay to the ASHA Leader, she said, "When audiologists and SLPs work together, children with hearing loss stand their best chance of success in school." It really comes back to the team and how many people are involved to making it work. Because everyone has got a different area of expertise and when they work together, it really can be a beautiful thing that helps our kids.

So we're going to top left. This is kind of community‑based support. Parent support activities. So the meeting yesterday started off for some family‑based organizations, and it was so impressive to hear in this room what everybody is doing in their states and every state looks different, with you are but the importance of matching families with others, I just got chills, with other families because that network just has a power that cannot really be described. It's just such a safe place. And I love that every state is doing things differently in a way that works for them. The Hands & Voices organization, what a unbelievable organization, helping families without bias against showing all of the different options that are out there. There's all kinds of different national organizations, there's AG Bell. We, in Massachusetts, have a couple that are specific to us, the hearing together group, we have two different ‑‑ or one different group that's kind of over by the Cape, and then Hear my Dreams is another parent support group.

And we also have the parent support groups kind of incorporated in our specialty service provider groups. So, for instance, we have a specialty service provider who as part of their program has a parent infant program. So the kids go off on their own for a portion of the time and then they bring the families together. And they'll have different conversations coming in with the families with different people presenting, but it's an opportunity for families to learn from one another.

And we had Dr. Lumerman in our state who retired but he was just such a leader in getting those conversations out so we can move beyond things that block us and move forward. It was funny, he could get people to talk whether they wanted to or not.

(Laughter)

>> Hands & Voices and, of course, Facebook and social media groups are another big opportunity, again, to provide that connection and that safe space to go.

Our program also, Sarah described a little bit, but we try to pull in and have different groups, whether it's social or whether it is educational, again, to really cement those parent to parent connections.

So the tree, to kind of summarize what we hope we have developed, is an overview. So it is not the detail, if you're looking to find what specialty service provider or you the detailed knowledge but it is that starting point to know that these options are out there and to have those conversations, hopefully with your providers, and dig in to leaves that you might not have known existed. And this prevents parents from saying oh, I wish I would have known, how did not know about, that because you can't go back, you can only go forward. But hopefully this will prevent that from happening. Remember, when you could be sitting with your early interventionists and things are smooth and they could be like, everything's going fine, have you thought about the family sign language program, the family could say, really, I'm not really sure what that is about, what is that about? And they could dig deeper in to well, it's a program a deaf adult is going to come to your house and it's for ten weeks, so you can really get into the details but it, again, provides, so you don't miss that leaf and say, when your child is two, wow, I didn't even know we had that. So that kind.

And it gross, things change over time, our decisions aren't static and they're never reversible, you can revert if you go this way and want to make a change, that is all good too. So what we're doing it with this now is we're distributing this to all families who receive a diagnosis for their child of being deaf or hard‑of‑hearing. They're given a parent information kit that can be overwhelming because there's a ton of information in it. But the more information the parents have, the more empowered they are to make decisions that work for them and for their families. So we're including that there.

And we're also distributing this to our pediatricians. You know, one of the things that came out of a recent meeting, an advisory board meeting, was one of the pediatricians said, this would be really great for all of the pediatricians to have so they know who is on the team and, again, to assist in that referral process. So we have started distributing that to all of our pediatricians and then copying the diagnostic audiologists as well just to bring everybody on to the same page and make sure we are working effectively as a team.

And then the next step that we have, we're going to translate this in to Spanish, and then our goal after that is to have this be more inner active and more on‑line. Our website is where we want people to go because it is a place that we can bring all of these different links together and, if we had this so that it was, you could click on you know, the audiologist and go directly to their, what they want to see on their site through ASHA, through the diagnostic centers, or you could go to the parent support organizations directly. So we would love to see that, and that's really where we're moving. It is not as easy as it sounds, but we're going to do our best.

And we had a suggestion this morning in our state stakeholders group to have this on your phone, wouldn't that be so cool, and just be like, click, click, click, and off you would go to get in to those deeper discussions kind of right on the spot. So we would absolutely love to hear your thoughts. Any questions whatsoever that you have, and we have a it ton of trees up here.

>> Oh, do you?

>> We do. And we would love for to you take some so that I don't have to bring them home because how do I end up with more stuff than I came with, like, right? I don't understand. So does anybody have any questions whatsoever? We would love to answer any. Questions in no questions?

Okay. Well, thank you very much.

>> Thank you.

(Applause)

>> Trees, trees, for everyone.