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Family Involvement and Leadership: Pathways to Success for Families with Children who are Deaf and Hard of Hearing

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>> Hi, everyone, I'm Emily, the room monitor. I put evaluations in the middle of the table. If you'd fill those out, at the end, you can hand those out to me. The name of this session is Family Involvement and Leadership: Pathways to Success for Families with Children who are Deaf and Hard of Hearing. I'll hand it over to our presenters now.

>> Good morning, my name is Sarah Stone. I'm director at the Massachusetts Department of Public Health.

>> I'm Jennifer Fleming, I work on the team as a special projects coordinator.

>> We're here to talk to you today about family involvement and family engagement. We're going to talk about the definition. We're going to provide examples and we're going to discuss leadership development. I think we all agree and certainly HRSA's leading the way, involving families in a program is absolutely critical. And I think we're all, also, willing to admit that it's not always easy and it does take, it does take a lot of time. It's not something that can happen overnight. And this is something that our program has been working on for many years.

And the other sort of lesson we were bringing to this is that you need to continue to bring families along in their journey. So... even though you may have families that have been involved in your program for a long time, you need to continue to develop the new families that are coming forward.

The definition from AMCHP is the intentional practice of working with families for the ultimate goal of positive outcomes from all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels for the individual, community, and policy level.

So... that's a mouthful, but if you're really looking at it, what's your, what you need to acknowledge is that families are the experts in their child. You want those experts on your team helping you develop the programs and policies that'll be moving your programs forward.

So... this is a very government‑looking type document. I'm sure most of you have similar documents within your own programs. And you won't be able to read it all that well, but I wanted to show it to you, this comes from our own Division for Children and Youth with Special Health Needs. Our core outcomes coincide with MCH's. What the first value is, we partner with families in everything we do. Doesn't say we serve them, we partner with them. I didn't put that emphasis for this slide, that's actually the way it's presented to our division. It's that bold, it's that sort of, you know... big print.

So... excuse me... family engagement is an integral part of everything we do within our division. We have a director of family initiatives that we work closely with and we're also engaged with increasing cultural competency within our own program and engaging families from different cultural backgrounds.

In many of our presentations, we talk a lot about data. And data is obviously very important, it's one of our value‑based methods as well. A recent presentation we gave, it struck me that you know... we do a lot of data reporting for CDC. We were able to say for one month, this is how many babies we screen, for diagnosis and intervention, but... what we didn't have was a real strategy about how to communicate what we are doing with families and our engagement policies.

So... we're able to say you know... we do X number of activities. This many families attended, we affected this many people, but we need to go back and look at strategies for evaluating, you know, what we're doing within family engagement and making sure it's effective.

So that we can include it in presentations so folks do know how important it is. It's something we work very hard on and we want it to be able to be represented. So... there's different levels of engagement and along the continuums. I'm sure many of you have seen, seen this before.

So... within direct care, families hear about issues and plans. Moving forward, families are a little more engaged, they share their experience, and then, sort of the ultimate goal is families are really partnering in their decisions.

They have information, they're able to make informed decisions about things that are going to affect their families.

If you're looking at more of an organizational level, you can do things like you know... survey families that you're working with, but... it needs to be authentic. You can't present something that looks finished and then say "what do you think about this?" And then, you know... kind of disregard what everyone's giving you for feedback and then move forward with it anyway.

They'll pick up on that real fast. This is something that you need to include families from the beginning. You can do surveys and you can talk about you know, different activities with families. But the next step and we all, have through our HRSA grants, learning committees, most of us have advisory committees, giving families a seat at the table. Not just one, sort of the idea of one family, in a room with you know, 20 professionals. That's not balance. You need to have more families involved.

And then, in the EAP forum, there's been several examples of how families have really led quality improvement initiatives. This may happen more for, excuse me... more medically‑complex children, but it's absolutely critical for children who are deaf and hard of hearing to be involved in QI initiatives within practices and within your own programs.

At the highest level, policy engagement. So... MCH is really good about including families in the needs assessments and things that need to be done every five years. You're asking families about policies and programs that you've designed, that you've decided are important. But... moving forward, it's really looking and asking what those families would like in policies and programs.

And then, finally, having families making the decisions about whether or not those policies and programs are moving forward. One of ‑‑ you know... as much as we don't like to admit it, but documents are value‑based documents. They're showing what's important to us and to our programs. So... if you're taking a look at your budget and again, now that HRSA's requiring we do 25% to family support agencies, that's actually, that's showing the value of HRSA and that's, in turn, making that the value of the programs, the newborn hearing screening programs across the country.

So... this is it all put together. It's a very busy slide, which is why we separated it out. But there are other factors that influence engagement. So... whether or not parents believe that they have a seat at the table... that materials are provided to them in a manner which they understand. Whether or not your organization's receptive to having them be involved.

And then... to the sort of society at large. Now Jennifer will talk about ways we've tried to make this happen in Massachusetts.

>> Hi there. I'm excited to be here. Before we get started, I'd like to find out, in the room, professionals we have and parents we have. If you're a parent and professional, if you could raise your hand twice, that'd be great. But... let's start off with professionals. Who do we have professionals in the room? Awesome. How about parents and families? Awesome. You guys are already doing family engagement. Everybody that raised their hand as a family in this room is already doing that.

So... what we want to share is some of the things we're doing in Massachusetts, but you guys have a lot you can share with us as well. Hopefully at the end, there'll be time for that so that we can all learn from each other. We'll start off talking about the Universal Newborn Hearing Screening Program. There's two parent positions in our group. The first parent that was hired was at the very beginning of the program.

So... this person is an Outreach Specialist and they work with families whose children have been diagnosed with hearing loss. So... I remember, very well, being on the receiving end of this call eleven years ago. I can tell you what an impact that position can have.

I remember being so vulnerable when we learned that our son was profoundly deaf and having somebody reach out to me, who cared about me, and had also gone through a similar journey, really, really made a difference.

So... I remember some of the conversations we had and how safe I felt in terms of asking questions that I probably wouldn't have been comfortable asking a professional.

So... I just think that's such an invaluable resource. I still remember this one time I was playing on the floor with my son, with JJ and there was a lot going on and the phone rang and I'm like "I have no time for this" and I looked over and saw it was my person. I don't know if I dropped JJ on the floor, I was lurching for the phone. That was a Lifeline. That parent to parent support is important.

In 2017, there was a new position that our group started. That's me. I'm excited to be the special projects coordinator. This position's different. It doesn't focus directly with the families, but focused on the professionals. Working with audiologists, ENTs, to develop learning communities. I'm sure you've heard quite a bit about over the course of this conference, but to come up with different projects like ideas and things we can do to make things better for our kids.

So... very excited to see where this goes and... hopefully you'll hear more good things. The other thing about this, both of these positions though, part‑time, have full benefits, which my husband's really excited about.

Next, I'm going to talk about the Advisory Committee. Sarah mentioned it's about balance. One of the things I found excited about the slides is the numbers. This is one of the Advisory Committee meetings. There's a lot of people in the room. The contingency is 14 people. Of the 14, two people are parents, two are consumers. This shows the importance of not only listening to the family's voice, but incorporating a family voice into all policy decisions and how our program is formulated, structured and changed. Pretty exciting.

The other thing we do to make this more accessible for families, because parking in Boston is like no joke at all, we do stipends to help families and make it easier for them to access this meeting and participate in the meeting, because it's very important.

The other thing, I think I saw Kathy Manfield come in. If you could raise your hand. Thank you. She's the chair of this committee and she is also a parent of a child with reduced hearing. She's engaged in all kinds of ways in Massachusetts including working with deaf and hard of hearing families as a social worker at Tufts and the parent group at Minute Man. That's extraordinary in Massachusetts.

Okay... what's next? So parent presenters. We have parents present in a variety of ways. One of which is a parent forum. This is an annual event that our group puts together to really focus on education for our families. We have parents present at this, stipends are provided, to make it easier for families to participate and the content is really influenced by what do the parents want to hear about?

So... this year, our forum's coming up on April 7th. It'll be all about education. How to educate ourselves and how to educate our school systems. And we're going to talk about the family sign language program and we're going to have middle schoolers on a panel talking to us about what works and how things look in their school, so we can all learn from each other.

So... this is really about parents educating parents, and professionals as well.

So... that's focusing on the families from a parent standpoint, but we also put together a lot of things for the kids. This is all about fun. You can see from the list of events we have here, it's targeted to getting the children together and having them know each other, know they're not alone and be together in our journeys.

So... in terms of family leadership and action, what that can look like. The first, ever, EHDI Family Leadership Award went to Lisa Adams. Many of you may know Lisa, but she's a force in Massachusetts. She put together a group of people and helped change the law. I remember going to the statehouse and seeing her son presenting to legislators. The room was packed and he was poised as can be and explained why it's important for children to have access to hearing aids and how sound is important. It was quite beautiful.

It really shows to me, the impact of how one person can make huge changes. And how there's leaders in all of us. It's a matter of how we choose to use them.

So... another great example of leadership in Massachusetts is the Shared Reading Saturday which many of you may be familiar with. A program really geared to teaching how to sign a book to our children, so you kind of learn how to sign a story and then you practice that in a pretty safe space with all kinds of different people and then, that's a skill that you can take out into the world. It's super fun. And we have this, north of town, but we didn't have this south of town. So... Parent Town, who is here, another great family leader, through funding through the program, she's starting this south of town. Really very exciting.

Another great example of what we do to engage families is working with the Decibels Foundation. We have here Naomi Shook [phonetic]. I think I saw you come in. Thank you. She's working with the Decibels Foundation and again, an example of family engagement. As the communications manager. And this group is responsible for raising funds to help our deaf and hard of hearing families throughout the state. They also put together a calendar to really share events so that everybody is aware of activities throughout the state.

And then, nationally, families have been contributing, such as examples include EHDI‑PALS.

In terms of identifying family leaders. We talked about these different events where we're together. The parent forum, family events, but there's also ways such as Facebook, where we tried to increase our presence and help share information, advertising, that kind of thing. But... also, I think another thing in our program that's unique is making sure that instead of relying on our service providers or external agencies, we have the contact information itself. So... Sarah has worked over the years to develop this e‑mail list so we're able to contact our families and reach out to them individually. I think that's made a big difference in terms of our ability to grow relationships.

For individual leadership, Sarah talked about how the individual leaders influenced here. I was inspired by what she said. But it made me think a lot, especially with her end quote, that inspiration, that fire within. As parents, that fire is there. We are driven to make things better for our children, certainly. When we get to a point where we're feeling comfortable enough in our own journey, maybe we can do something more to make other families lives easier, better or in some way, to give back. Being so grateful for what we have benefitted from. There's ways to develop these individuals that might have that spark. I went to the Family Leadership Training Institute. It's a training opportunity in the state, it's not about deaf and hard of hearing children, but about any parent with a special Health Care need, child with a special Health Care need and was a six‑month training telegram. Five different weekends where this group would get together. You're locked in with your cohorts and get really close with these other individuals and it was very clear to me that we share such a common bond. Whether your child is deaf or hard of hearing, or your child has cerebral palsy, there's a lot of commonality and we can really learn and grow from each other.

So... I think there's a lot of different training opportunities to grow leaders that exist, that might be beyond you know... a scope that you might typically look at. That was a phenomenal training opportunity. It really showed too, a lot of the people that they brought in to help develop this leadership, if you will, was individuals, like ourselves, who had seen something they wanted to change or make better for our own children and they would affect this global change, just by having an idea and feeling that I can make a difference. So... they talked about skills and developing leadership skills, but they also talked about how it just takes that spark to really make change. And giving the supports as well. That's why I think the professional partnership is so important because you want the support that those families need to really get in there and make change. Because it doesn't happen alone.

So... the other thing to mention is the EHDI family sponsorships. Are any of the families that raised their hands, representing the states on the scholarship? Yep? I'm going to say that, I came here ‑‑ not here, to Louisville, couple years ago on the EHDI scholarship for Massachusetts and that was a pivotal change for me. I was so blown away by the other parents that I met, the families that I met, the professionals ‑‑ I just, that I met ‑‑ I just was completely overwhelmed. The collective passion. Every single person I met was so passionate about changing lives for families and making things better for deaf and hard of hearing children. And it, it was overwhelming. So... I stand here now, I'm just as overwhelmed, if not more so, because I see all the things we can do and make they are together.

So... yeah... I think that's a great opportunity. This year, we were able to sponsor five individuals, which is a lot. I've seen states here with, my goodness, like 14 individuals and... I just think that's terrific way to start. When I think back to Louisville, a couple years ago and the parents that were in the room at the parent event, versus this time, it's a considerable change. So... I think that we're already doing a lot of family engagement.

And there's other conferences that we fund families to attend, which is Family TIES. Massachusetts Matching Program helps match families new in the journey to families that are farther along. We help train individuals to be great mentors for their families. As we learned so much from Hands & Voices and throughout these conversations and this conference, presenting unbiassed information and presenting all kinds of different options is so important to families.

So... I would love to turn it over to you in terms of questions that you may have. And maybe ideas of family engagement in your state so we can learn from each other. Do you have anything you'd like to add?   
 >> If there's any questions, whatsoever... that you might have about our programs, we'd love to share more information. Does anybody have any questions? Does anybody have any examples? Please? Thank you. Hold on one second, we're going to CART in. Amazing this technology.

>> Hi, I'm Carmin from New Mexico. I was interested in the family forum that you have. Like... how did you guys kind of get that started? And... what ‑‑ what are the topics you talk about during that family forum? How did you come up with those things too? That's where I'm kind of stuck to come up with ideas and you know, who do I get to present those ideas? Is it from my experience? I have two hard of hearing children... is it based off that? Is it ‑‑ you know, kind of ‑‑ how would you get started?   
 >> I love it, that's a great question. Sarah, you want to start?   
 >> I think we're on our seventh year of family forums and it sort of started as we were doing these, more social events and we felt like we needed to bring an educational component in. But... it's hard to get families to you know... to, to give you a whole day for something. So... we had challenges. We had 40 people or so who attend each year. But... we've tried different areas of the state. We're trying to reach you know... different audiences, but as far as the topics... they're really driven by the families. So... some years, they're, I don't want to say softer topics, but more practical things like... sports and how do you ‑‑ how do your kids participate in different activities and what do you need to think about as far as helmets and what do you need to think about as far as educating coaches. We've done things on literacy. We've done, you know, things specifically about IFSPs and IEPs. The topics are really driven by the families in the state. So... we reach out to them throughout the year and ask what, you know, what topics would they like to see? And our presenters are primarily, either, parents or they are deaf and hard of hearing teenagers. We, one year, actually, almost every presenter was, was an individual who had a, who was deaf or hard of hearing.

So... we try really hard to make that happen and... I think we've been successful. We've been able to ‑‑ they don't cost a lot of money, these are events, you can hold them locally and you know, hold some, have some catering and you're pretty good, you know... that's the practical aspect of it, but they're really parent‑driven.

>> And this year, as well, just to add to that, we're opening up a little bit, making it a little different. Before it was this is what we're doing for parents and kid events, kind of separation, but this year, the kids are invited as well. We have the middle schoolers ‑‑ I think that's going to be a very different dynamic. We'll see how that impacts what we want to do in subsequent years, but... yeah. See what works.

>> Thank you, I think I saw a question back here? Oops! I'm sorry. Okay... you're next.

>> Just basing off ‑‑ or building off that. How do you focus on kids? You don't just do zero to 3, you do middle school. Do you have topics where it doesn't apply to each family? Do you have different sessions like a typical conference would? Or one session and it's kind of ‑‑ everybody goes to that and if it applies, it applies, if not, it doesn't?

>> So... we haven't expanded to the point where we have concurrent sessions, although, that's definitely a goal. If you have a younger child, some of these things may not apply. But... that said, kids are playing soccer at age 3. There are certain things that people can take out of the day and it is, you know... preparing families for what's to come. So... as we're doing education this year, we have gotten a lot of interest from families to bring their you know... their 7 and 8‑year‑olds to see the middle schoolers, I think that's so important for the, for the parents to be able to see, is this where my child's heading. And for the child to see, this is where I'm heading.

>> Also... I think, you know... as we were structuring this year, we were thinking about who is going to be coming? What are the ages of the kids? Originally, I was going to say we, but I was thinking, we should do IFSPs, we should talk about [indiscernible], the zero to 3 won't be represented in that group. It's very dependent on who we think is going to be there and who we think we can capture. So... I think in subsequent years, depending on who we think or educational needs and what the parents are telling us, we'll really focus, focus in that direction. Thank you.

>> Okay... I'm from the island of Guam and... I was really impressed last month, last month, February, Hands & Voices came and did a really awesome three‑day training and first, first day was basically speaking to the parents, second day as well, but that evening on the second day and the third day, they had also, not only the deaf and hard of hearing children, they were younger or teenagers or siblings coming. What they did, I'm really impressed, I hope Guam will pattern after that, they separated the parents with the hard of hearing and deaf and hard of hearing, they had their groups do activities and programs and question and answers that Stephanie and Karen did with the, with the, with the deaf and hard of hearing children, adolescents, and then, Candice did the part with the parents and I think that was really good because... many times you know... the deaf and hard of hearing, they did share that. I attended [indiscernible] to the other, they are limited with friends and... socialization skills and bullying issues and that kind of stuff and the embarrassment of wearing the units. I want to just piggyback off that, how Hands & Voices did that, so ‑‑ I was really impressed.

The other question that I also had or have is, the IEP, in Guam, the Guam Services does a lot of training for the IEP. That was brought up in the meetings where the National Association from Austin, Texas came out a few weeks ago. They were talking about IEPs and IFSP and... the local school system said, we have them, so many times a year, to treat parents. But... it's very hard to get the parents to come and attend.

So... my question is, piggybacking off the first lady, would it be more helpful to have parents who have kids, deaf and hard of hearing children in high school as well as older children that have gone through IEP versus having the professionals come in? And... I ask that question because it was on the parents. I'm a parent. My daughter will be 27. She's hard of hearing. I'm also a coordinator for the parent support group. We had our first parents book review, (?) There were a lot of technical IEP meetings. The terminologies and stuff, it was like... they're tired of that. I'm wondering, would it be more effective if we have parents with experience to you know, be very open, frank... talk about the experiences and what works and what doesn't work, versus having the lawyers or the school system come in and talk about that.

>> I think that's a great question. You definitely have your hands full, so congratulations on all of that. I think it can definitely be a combination. That's one of the things I love about the programs approach to doing a lot of different events. The kid events, yes, it's all about fun, but you'd be surprised, the parent to parent conversation that takes place, the accommodation, changes that I'm making for my son's IEP, based on conversations that I had at Legoland are real. Those are happening. That had nothing to do with professional involvement, but at the same time, it was all fostered by the program. One of the things I like about the forum, it gives structure as well. It's the parent to parent component, but also brings that professional piece in so we can dig deeper. I think it's such a partnership, yes... the family to family connection is super important, but that professional component is huge. There are so many professionals that affect our children's lives, the better we work together, the better it'll be for our children. I'd love to see different events because ultimately you want the families there. You want them engaged and talking. In whatever form that looks like in your state that you think that would work. I think that'd be a thing of beauty.

>> It's time to move on.

>> Thank you, guys, so, so much. I'm really grateful. Thank you.  
[applause]

[Presentation concluded at 12:11:00 p.m. ET/10:11:00 a.m. MT].

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