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Parental Communication Competence and Early Intervention

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>> Hello, everyone. Okay... the mic's on ‑‑ I'm the room monitor, we have Melissa Jensen here for our next presentation. At each table you can see evaluation forms. As you're done, fill them out and put them at the back table. Thank you so much and enjoy.

>> All right... good afternoon, everyone. My name is Melissa Jensen, like they said. Here's some information on me. I'm a Deaf Educator as Carle Auditory Oral School and the parent of a 14‑year‑old deaf child.

I'll tell you about this project I've been working on for several years now. That's where all the information I'm going to be presenting today is coming from. When I was in grad school, we had to do something called a learning project and... that was the beginning of the information that I'm giving to you today. It, then, became an EHDI poster two years ago, when I was still a student and yes, it won outstanding student poster. I had to put that on there too.

I changed it to article form to be in Volta Voices and today, I'm going to present the information that I have found.

What we're going to talk about today is the process of communication and... the cycle it takes. So... very early communication begins by being responses to crying, eye contact, cooing and this circle that the child and parent go through builds confidence and skills so that a caregiver, as they comfort the child, they learn they are competent, they are successful and the child learns they can trust the parent to comfort them and provide their needs when they need them.

So... the question is... what happens when this cycle is interrupted by hearing loss? So... a child doesn't understand the comfort that's given through auditory means and the parent begins to feel frustrated and the bonding becomes impacted.

So... how do parents learn to communicate, sooth and bond with their child? How do parents become empowered to grow their child's language, so the child can reach their full potential?

If we think about it, parents of children with hearing loss are in a very unique situation. They are faced with being the primary language model for a child with whom they have limited skills to communicate that. Doesn't happen in a deaf of deaf family and it doesn't happen in a hearing of hearing family.

Researchers have discovered that language outcomes for these children are significantly tied to the family's ability to communicate freely and fluently. So... do parents of children with hearing loss feel competent communicating with their own child? And if they do, how do they achieve that level of competence? What were the steps to get there?

So... throughout this presentation, I'm going to put up quotes because... I feel like listening to the words of the parents that I spoke with are the most‑important part. So... this is my first question. "In the beginning, I felt like I'd been given the wrong kid because there was no way I was good enough to meet his needs. I was sure I'd screw up and make wrong choices on his behalf." This is what parents are feeling and living with in the beginning. To explore parents reflections on their competence, I conducted interviews with 22 families of children who are deaf and hard of hearing. The children in the families I spoke with had children who ranged in age from under one year to over 24 years old. The families, a variety of communication methodologies from bilingualism, like American Sign Language and written English to signing supported spoken language to auditory verbal therapy and listening and spoken language school placements.

So... 22 of the parents had typical hearing, one family had two deaf parents and one had one deaf parent, one hearing parent.

I also, as I said, I talked to a variety of ages. This is kind of the layout. 14% were under a year old, 36% were pre‑school and early elementary, 27% were mainstreamed and 23% were teens/adults.

So... what did I find? I was able to ask them to describe their experiences and emotions about their ability to communicate. With their child now and at the beginning of their journey. Since I had many different ages, people talked about how they felt at the beginning, how they felt now, and... the parents of adults talked to me about transitions and things like that in their lives.

I also requested information about the role of professionals in early intervention and building their communication confidence.

So... I went through the materials that the parents shared with me and I looked for patterns and recurring themes. These are the five patterns I found. Diagnosis, early intervention, feelings and emotions, trusting oneself and us, the professionals.

So... my findings were that parents were extremely confident in their ability to communicate with their child and this is the biggest part that got me, no matter how recent the diagnosis was. So... even early in their journeys, the parents felt competent. Many of the families expressed that they struggled in the very beginning, both with knowing how to develop a shared language and with feelings of grief. But... the key was that they reported that once they'd been given tools through early intervention, auditory verbal therapy, school, or other EI professionals, they gained the confidence and their skills to develop a clear and useful communication pattern within their family.

This parent confidence was evidence regardless of the language used. There were a few additional worries for ASL users. These parents reported concerns about learning English as a second language, becoming fluent in ASL themselves and then resources for learning ASL and resources for their child, providing an education in an ASL environment.

Also... the confidence of all of the parents was very dependent on having access to professionals who helped the family build their skills.

Here's another quote, two quotes from parents. I felt like diagnosis and the years to follow were like living in a tornado. You're just swept up in a world with new language, life is full of appointments and you become a fighter.

Another said: When he was first diagnosed, I didn't know you could teach a child ‑‑ teach a deaf or hard of hearing child to talk. I was devastated. We began early intervention, when he was a few weeks old with an oral School for the Deaf. At first I felt uncomfortable, unprepared, uneducated, overwhelmed, angry, sad and unsure if he would ever talk and be part of the hearing world.

So... what about parents who do not feel supported? Those who do not have access to good early intervention services that were useful for them to build language and communication competence? These families reported that they continued to feel overwhelmed, they didn't see success in communication, which then, led to fear and doubt about themselves and the progress of their children.

So... as we think about the steps going up, so they receive unsupportive services, they don't build that confidence in themselves, so they're overwhelmed, still and emotional, then their child doesn't learn, they're not getting good feedback, they're not making progress and the parents continue to feel out of control and in competent and the child continues to make no progress and it's just a vicious cycle.

So, here's what a couple parents told me about having poor services in early intervention. "I feel like he's so far behind and I feel like it's my fault. My biggest concern has always been that I wouldn't be able to teach him what I need to and I was right." Can you imagine what that feels like every day to be that parent? I had these worries at the beginning, that I'd fail at this and I did.

Another said: EI did nothing for me but harass me. I taught myself sign language and then I taught him. I had to have a way to communicate with him so I found it and I held on for dear life.

This is another family that wasn't supported in a way that they wanted. So... maybe they had really great services in a different modality, but that wasn't what the family wanted and needed. So the parents didn't use those resources and feels like the only thing that early intervention does is harass you and tell you you're wrong and... I can't imagine having to live with that every day, to have to seek it out on your own so that you can get the ability to communicate with your child.

But... what about when things are going well? So... this is the good news. When parents ‑‑ hold on. So... based on the responses, I asked the parents more in depth questions about what exactly it was that the early interventionists were doing that was so helpful? Was it support they were providing? Was it language development strategies? Information about hearing loss? But... the parents I spoke to, very rarely reported specific strategies. Being of great importance.

Now, as a teacher of the deaf, I'm all about the strategies. Use this strategy and that one and I have them up on my wall in my classroom so I remember to use them all. That's not what parents are saying. They're saying, the professionals taught me to trust myself. And gave them assurances that they had the skills to actually provide language for their child. That's the role of early interventionists that were missing sometimes. To provide parents with the skills they need to communicate to support them in the beginning when they don't know if they can do this.

So... at the beginning, on this slide, we have the same thing. Overwhelmed and emotional. And then we receive our services. Which was the same as the last one. But... this time... they gained confidence. They were able to see that what they were doing was working. Their children were growing language. And that makes them feel in control, that makes them feel competent to communicate and take the next steps.

So... often we talk about self‑advocacy. We're going to have these parents at the IEP meeting and they're going to run the meeting and they'll be ready. If we haven't given them the skills in birth to 3 to do that, they'll never be able to sit down with the school district and say "those goals aren't appropriate." If they're still scared and not knowing "I don't know how to expand this language and he made that sign and I don't know what it means." Then they're not going to sit across from a bunch of professionals that say "this is the right way to do it and say no, that's not right for my child."

A couple more quotes: I'm confident in my ability to teach and improve my son's language and communication skills only because we have been an active part of his therapy and appointments since day one.

I think that's really critical. The parent recognizes that it's, it's work. She has to go and be a part and not just sit back and be like... okay, you therapy my baby and I'll be over here washing dishes.

If we start when they're still so young in birth to 3, we can give those skills to the parents. We're not the gate keepers of all knowledge. Give me your child and I'll give them language because I know all the things.

Our job is coach. And empower. And teach the parents so that they can do the language when we're not there. We're never going to be able to teach language in an hour a week, if you're lucky.

So... the next parent said "I do feel competent to communicate with my children. I learned so much from our therapist who was amazing. I took my child every week because I felt she really supported our family and was the perfect fit for us."

Again, this was a parent who said "this therapist is giving me what I need, so I'm going to holds onto them for dear life." That's what we want to be. We want to be the person that they know, when I'm down, when I don't know what to do, when I'm struggling, I can tell this person. They're not going to judge me, they're not going to tell me I'm wrong. They're not going to chastise me because I'm struggling, they're going to tell me you're doing it, you can do it and here's some information or some skills that will help you do it."

All right... I have some more quotes. It's more important to hear from them than from me. This person said: I really needed the direction of the Early Intervention Specialist at first, but now I feel like I've got it down. It does still help when their SLP reminds me of something they notice that I might have overlooked.

So... empowering parents is great, it's never going to put us out of a job. They still need us and they need professionals throughout their lives, but the needs change. So... in the very beginning, in birth to 3, the needs are the parents. As we transition to school, as we go into part B ‑‑ right? Part C? Part B, okay... I'm like ‑‑ which is which? Then the families will become facilitating the school. Because... all kids, eventually go to school and the parents are a great part of that.

But... in birth to 3, we are working with the family on the family's needs. We are focused on coaching and... helping them develop the competence to do the things that they need to do, the other 23 hours in the day and... when we front load like that, then they can stand up at the IEP meeting or... when they're headed to college, they know that their child will do okay, because... they have the skills and they've been with them throughout the entire journey.

We change and we change often. It's very unlikely that you will see the same child from birth to 21. It's just not going to happen. Mom will be there. Dad will be there. Grandma, grandpa will be there. Those people are the ones in their lives when we come and go, they're the ones we need to empower to be able to do these things.

Oh, nope. I forgot something. Let me go back. So... another quote: In the last six to mine months, despite ‑‑ I really love this, we'll talk about this in a minute ‑‑ in the last six to nine months, despite the fact that she has a significant speech delay, I'm worried that I'm not crying and as concerned as I was the first three years after she was diagnosed. I know that there's not one single thing that I haven't done for helping her develop speech and language. At this point, it's just a matter of time.

I love thinking about this parent who realizes very early in the journey, they were crying all the time. They were so overwhelmed and worried about everything, will they be able to do this? Do that? What about college? What's going to happen? Will they ever get a job? The parent stopped and said "I don't know when the last time I cried was because I know they're going to be okay." I'm doing the right things.

I like to compare this quote to the one where they said that EI was doing nothing but harassing them or they knew they had failed. Just the difference and the only difference was the role of the early interventionist in their lives.

Whether or not they were taught that they can do this. They were lifted and... supported in that time of need at the beginning.

So... what can we do? My conclusion was, as providers, our job cannot only involve the traditional information for parents about hearing loss and language development and strategies for communication, so... we read our IFSP goals, you know... he will communicate with friends and families in various locations, you know? That's great. But... what about the family? What are we doing to make sure that the parents or the caregivers understand that they have the ability to do this? That yes, their child is deaf or hard of hearing, and that was a surprise. And this is a new path that they didn't know they were going to go on... but they are strong enough and they are smart enough and they are good enough that they can still lead their child.

We must support families and help them build confidence in their ability to successfully communicate. This confidence builds and as parents communicate and build the language of their child, they emotionally strengthen. They use the specific strategies that come later because if I'm teaching about acoustic highlighting, or even joint attention, and all this mom can think about is "my baby can't hear me, why am I doing this? You told me they're deaf, they're never going to talk" or "I don't know enough sign, I can't do this, what if a word comes up and I'm in the grocery store and I don't know that word? I can't do this." If we teach them that they can, let's be real, none of us knew any of this at some point either.

If we teach them that they can do this, they don't have the wrong child... they can, then, take the information that we're teaching about in audiogram, or that we're teaching about strategies or language development and use it. That they can't do that until they're strong enough to learn from us.

So... empowerment, in the end, is the greatest tool in strategy that we can ever give a family. That's the end.  
[applause]

We have a few minutes left, does anybody have any questions? Do we have someone with a microphone? You can do it for me? I took off my shoes. This one? Is it on?

>> My name's Laurie, I'm a parent and my question is... how do we get consistency with the early intervention services that we're delivering state‑to‑state, county to county, personally, we've moved to a different county with different resources, which is great, but... we're still seeing so much inconsistency across the state with delivering those services and the support to parents and personally, like... I'm still in that negative place because... my child isn't even following you know... we're not getting the results that we were hoping to get with our initial communication plan. So, I guess my question is, how do we get that consistency across the board for EIs?   
 >> I completely agree with you. As I said, my daughter's 14. We started in one state and ended in a very different state. And... even between providers within the same school, there was inconsistency. I think it's our charge as EI providers, as people who are educating EI providers, so... in university programs, that we need to look to the parents. They know their child ‑‑ I know we say that, but do we really believe it? Do we really believe that parent knows more about that child than we do because we are the almighty professional?

So... I'd say that right now, it's not fair. Where you end up being born, the geography of your life ends up with your opportunities. And... I hope that eventually system‑wide, we're able to make those changes, but... I really don't have a good answer. Anyone else?

>> So... are there any standards of care or is there a rubric for early intervention? Specific topics or... modules you're supposed to be addressing throughout birth to 3?   
 >> It depends where you are. Some schools have specific curriculums. Sky High is one. I've used ‑‑ it comes in a little box. Do you know what I'm talking about? There are specific Talk Around‑the‑clock, yes. There are schools that have specific curricula that go through all the areas of knowledge that we want parents to have. There's a resource by CID that talks about the areas, the nine domains of early intervention. That's really good. In how to, if you go to CID and under resources, it's there. It talks about the ways to write goals as well for those nine domain areas. One more?

>> I wanted to add on. I went to a presentation on Sunday, it was about fidelity of early intervention services and developing a curriculum protocol to do that and it was actually really awesome. If you didn't go to that presentation, it was put on by Nannette and her website is [indiscernible]. It's got tons of good information. It breaks it down between skills providers should have in 16 different areas, and includes strategies and it's a self‑rating tool to rate yourself as a provider in how good you are at those things and your families you work with. So... look forward to that, it's still in draft mode.

>> Awesome. All right... thank you, everyone. Go have lunch.   
[applause]

[Presentation concluded at 1:59 p.m. ET/11:59 a.m. MT].

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