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EHDI – Florence

Bridge to Preschool: EHDI Foundations Leading to Success

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March 4, 2019

2:15 – 2:45p

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[Live captioner is standing by].

>> We're going to get started. This is Bridge to Pre‑school: EHDI Foundations Leading to Success.

>> Good afternoon, everyone, we are your presenters today. We'll introduce ourselves. There are so many transitions within EHDI, even within the 1:3:6 and transitioning into early intervention. Today we're going to be talking about that transition from out of early intervention into the pre‑school. And you might ask yourselves why does that ‑‑ what does that have to do with EHDI? That's later down the system. I want to start today by telling you a story. When our family went to our transition IFSP to IEP meeting, I'm sure there were people that told me what that was going to be, all I remember thinking is... wait, what? Our early intervention provider isn't going to be working with us anymore? Can you imagine being in that moment and that's what was occurring to me at that time.

Today... we're going to be thinking about the transition from early intervention, into pre‑school and... some of the components an the complexities of that.

So... when I started thinking about it personally, I was thinking, a lot of times in systems, we talk about the linear process, so... we think about that, yes... families go through the 1:3:6 and they'll enter into part C, which is the Individual Disabilities Education Act that has to do with birth to 3 services and onto the transition to part B school age. There's a lot of different ways we can think about these transitions through the system, right?

Thinking about it linearly, like I just mentioned. There are different laws that oversee the components and the complexity of what's happening within them. Sometimes people think in terms of their systems roles. So... systems builders will say, you know what? We are ‑‑ we are here to do screening, identification, and enter into early intervention ‑‑ that's where our role is. Even that may be true, but if you don't have at least a platform of understanding of what's coming up next... what I like to say is, you can't build a foundation of what families need in order to go to the next, the next thing.

Often, and realistically, there's different funding streams that fund certain items and then, again, thinking about those transitions that families are going through.

To top all that off, individually, individual state, and territory systems may also have some complexities built in to how this goes. For example... some states may do, provide part C services, rather than birth to 3, birth to 5. So... there's always ‑‑ I thought I'd just start with this, this slide, in terms of the complexity of it. Don't worry, our next presenter is going to come up and break it all down for you, except that I would like to say, from my point of view, I like, at the end of the day, with all of these different elements, to just sort of sink into the idea, if we think about it, from the perspective of the family journey, as they're moving through these things, honestly, when we buy the birthday cake for our 3‑year‑old, we don't put on there "hey, welcome to part B." You know... these are not organic transitions for us, they've been built into systems. So... we have to figure out how to navigate them.

I do want to say that there's always conversations about, let's create seamless systems for families and you know, whether that's a fact or a fiction, whether we can actually do that, because of the complexities, I do all ‑‑ I always do believe that wherever we stand, in the system, and whatever role we're playing, that there's actually elements we can build in that will serve a family in the future.

So... here are some of the laws that are looking at that, this area around the EHDI Act. Which, which is the legislation that talks about what we're supposed to be doing in the EHDI system and it doesn't just talk about entry into intervention, it talks about intervention services. We have the Joint Committee on Infant Hearing as well as recommendations for early intervention.

The Individual Disabilities Education Act are the parts of the law and legislation that have to do with families who are in birth to 3 services and... then, on into part B and then, again, as I mentioned, transitions in a family's life. What can we do? I'm going to turn it over to our next presenter, Cheryl, who will talk some more.

>> I think I just got a shock. So... one of the challenges that I think we have is that part C is a generic system, when you compare it to part B, which is categorical by disability.

So... sometimes we struggle working with our part C systems to help them recognize things that we think are really unique to what we want part C services to look like for our deaf and hard of hearing children.

So... one of the things that I have found that's been helpful is to actually do a crosswalk between what part C requires in terms of their reporting indicators, what the JCIH goals are that support that and then... the knowledge and skills that are required by the providers in order to support the JCIH goals and eventually, have that funnel in.

So... I know you can't read this slide, but I wanted to put that up as an example. This particular indicator refers to early childhood transitions, specifically about transition, out of part C, into part B.

But help our part C people who aren't experts in deaf and hard of hearing development and education understand how we can align the best practices underneath what those goals are for reporting.

So... there's a couple areas where we really look at what does ‑‑ what do we want represented and one of these that's been happening in individual states are the language and literacy legislations. They may be under the umbrella of what we call LEAD‑K. I know there's many struggles in states. I'm very pleased that AG Bell and the LEAD‑K group came together and found some common ground and now we have model legislation that we can all refer to that includes all of our children and there's a lot of misinformation out there about, takes away parents rights to choose and other things which are really not true.

What I want to focus on is a couple things, why I feel that legislation is really important. And one of them is accountability.

We don't have, within the part C system, a way of assessing children and have agreed upon, in our state, markers of progress that we can look at, specifically for language and preliteracy development.

When we want to track our children, they're in the whole system, of all part C‑eligible children, there's no categorical definitions.

So... we don't have a way of looking state‑wide at how are our children really doing as they're in the part C system.

Minnesota is here and they have figured out a way ‑‑ I love it ‑‑ to actually track their babies up into the education system. That's what's really important. That's what would be required under this type of legislation... so... the ability to follow children from part C into school age to really track the progress that they're making. And then, over time, we can look at what could we do differently, if they're not making the expected progress.

And... it doesn't ‑‑ the assessment under this legislation typically just adds to what the IFSP and IEP teams are already doing. I know there's controversy about it usurping the responsibilities of those already existing roles under IDEA and that's also, not true, so there are factors in this if your state is looking at some kind of literacy and accountability legislation that I think is critical to what we need to know about the population of children that we're serving.

So... some of the challenges that I see in transition, really, one of them, sort of starts in EHDI and it seems like EHDI wants to end at the point of intervention of passing that child off to the intervention system. And that's ‑‑ and not really having a lot of involvement in what does that intervention system look like.

And the other part of that, I think, is how we treat families and I loved our opening session this morning, just about how we treat people and it's so critical that families, from the very day that they're told their child is being referred, be treated as a human being and is asked how you want to proceed. This is what needs to happen. Let's see how it works into your family, we're going through the referral assessment.

My point is, how we treat families early on really sets the stage for families becoming empowered as they move into part C to have a stronger voice in their early intervention programming.

So... I think we have to look at how EHDI rolls out in our states and how well they support the actual intervention that occurs. I think that we also have our biases that sometimes interfere with what is told to parents about choices and options and programming that's available and when does our personal belief system become a bias? What are our assumptions about the development of deaf children. What assumptions do we make on that first home visit with the family, when they live in a trailer court that's a high poverty area with lots of drug involvement and maybe we don't want to be there, but... immediately, we get a picture and an assumption of a family that may not, at all, align with what that family experience is.

Special factors and special considerations under IDEA, in part B, doesn't exist in part C, but... the communication plan, I think is a really important component that we should somehow, bring in from a parent's perspective, so... that's part of the discussion. With our child, while they're in early intervention, so that that carries over with the family into part B when we're looking at their eligibility.

Assessments is another area of concern. What are the assessments that are being done? Who's qualified to do those assessments with the infants and families and how do those assessments impact eligibility when children transition to part B?

We see more and more babies not meeting state eligibility part B regulations. And... is that because our assessments aren't deep enough to identify the gaps that might be there because we're relying on the generic assessments that are often done in that child find transition process? Or... is it for some other reason?

So... we want to be proud of our early intervention services and how much they have promoted that family and that child's development, but not to the detriment of them not being eligible when they transition into part B. And if they truly are doing well, what will that system do, knowing this is a very much at‑risk child, what will the education system put in place to monitor those children very closely? If they're not receiving services.

And are they getting a 504 plan? Are they getting other access, kinds of support. If they're not eligible ‑‑ we have to monitor them, we can't be in a situation where we wait for them to fail and the education system has become a failure‑based‑type of model.

And lastly, the autonomy of the family is one of those things that's very fragile in the transition process. Because as Janet said ‑‑ we've gone from a very family‑friendly focused direct intervention program to one where the family is one voice. The family being one voice at that eligibility meeting and going on into IEP meetings is really, really hard and I always tell parents, bring somebody with you. So that you have somebody you can reflect on what happened. And don't ever feel that your pressure to agree at anything in that eligibility meeting or... even any of your IEP meetings. If you're not real comfortable with what's being shared and recommended for your child, you're not under any obligation to sign or prove anything at that point. You can take it home, you can think about it, you can talk about it with family and friends.

So... those are just a couple thoughts that I had. There's a really nice document that came out recently between CDC and with work with Hands & Voices, making a plan for your child, and it's a great document to help with this transition process. Janet, are you going to talk about that more? No, okay. It's on the CDC website.

Some other things to consider ‑‑ have a list with you. It's easy for them to say "we'll provide X number of teacher of the deaf services" or "we'll have technology for you," but think about the wellness of your child. The wellness and social emotional development. That is often over‑looked and for young children, this may be the first time when they're in pre‑school that they're in a, sort of more‑formal type of arrangement. There may be issues around social‑emotional wellness that need to be considered.

Make sure that all of the communication access accommodations are provided and I'm not a proponent of having an interpreter in a pre‑school classroom as an accommodation. Unless that interpreter understands a role of being a language facilitator. Sometimes interpreters don't understand that and that's not been part of their training. There may need to be somebody else who becomes that facilitator of language between the children that are in that pre‑school setting.

But pre‑school children are not cognitively ready to have a teacher talking and then an interpreter signing. So... we have to look at the cognitive development and what's developmentally appropriate at the pre‑school level.

Assistive technology, make sure that's all available and it's being monitored. Family training and counseling is still part of the family services that are related service under part B. So... you want to make sure that's part of your discussion for the IEP and it's very often overlooked. This is services that you could still get in the home or that are directed to you, any service that would help your child meet their IEP goals. School district would be obligated to provide to parents.

And I'm going to stop there because I talk too long ‑‑ you can see the slides. They're online, you can download them. And I'm going to turn it over to Carrie.

>> Carrie: All right... we're going to move along. So... Ohio has adapted the Bridge to Pre‑school resource. This is what I love about the Hands & Voices community, I mean, I literally made my career of being like "would you mind if we made this for Ohio? That'd be great!" Including Communication Plan, but Bridge To Pre‑school is one of those. It was a nice collaborative experience. We had a work group of providers and state agency representatives, a nice diverse grouch people where we went through the whole document and made sure that it, you know... meshed with Ohio regulations. I'd like to say this is being used all over the state, consistently, regularly by providers, but that's not necessarily so. There are a handful of providers who use this. I asked "what does that look like?" You send these things out into the ether and wonder "do people use it?" And how do we know? We don't have a mechanism to track how these resources are used, but just educational audiologist and EI provider, I added the bold emphasis here, but... parents have transition questions way in advance. So... clearly there may be families with a six‑month‑old that it's not an appropriate time to hand over this whole document that goes through, you know... how to set up transportation and all the differences between part B and part C services, but... there are also families who would like to have that information right now. They may not read it right now ‑‑ they may not be ready to process it all, but... having that resource provided, you know, early in the game, can be helpful.

I also, like this came up a couple times, the EI providers are typically the ones, probably not a surprise, advocating for educational audiology services and teacher of the deaf services, because they're working with schools that don't have that experience. Those EI providers need to be at the table. They're the ones that know this family. They know each other, so... you know... dropping this little person off at pre‑school, without sort of some background in context is important. Those EI providers can do that.

Another quote, service coordinators talk about the process frequently and we know we need to hear messages multiple times, but there are lots of parents who like to read through all this information. It's a long document, 44 pages, so... again, breaking up into smaller chunks, anybody here that's an educator, quite familiar with the concept of chunkier information. So... yeah, it can be ‑‑ they said it was ‑‑ this provider said it was helpful in being able to sort of pull out a piece at a time and go through and talk about it and probably going back through again and again.

This document does have citations for citing IDEA which is helpful as well. This is not just, you know, what we believe to be true and what we would like to happen, but it is based on something more than, more than what we want to happen.

So... I think those annotations are, are in really nice, sort of strength to this document.

I liked this last quote here... so I liked links to information about the laws, but allowing parents to fill out information about their child. I always discuss sharing a vivid picture of the child. I love that. Vivid picture. On the spot, we know, we have one parent, we have all these professionals and like... so... tell us what's your vision? I mean, we have a lot of discussions in our state about, I mean, parents being like... that has to be a lot of anxiety to like, all of a sudden, throw out my vision. We don't know what we're having for dinner tonight, so... no, I don't know. I hope my little person has friends and learns to read and write and all those things. Using that document to guide those discussions, like... what's your vision. When they're at the IEP table, they're ready to have something to say about it. I echo Cheryl's sentiment, there's no need to go into an IEP meeting alone if you're a parent. I'm not a parent of a deaf child, but having had to play that parent role over the years, you need to have an advocate or somebody alongside you.

Last quote here... letting families sort of just sit with this information, revisiting it over and over, and again, the quote is "I'm usually the one advocating for education audiology as part of the team because our districts have very few children with hearing loss." So... that transition piece ‑‑ I mean, you're talking about the professionals on both sides of the table, part B and part C coming together and... that doesn't always happen, I mean, I have to say, in Ohio, we still hear stories of EI providers being like... they have a whole meeting and we didn't even get invited, we didn't get to share our whole piece. I see like heads nodding ‑‑ a resource like this ‑‑ it's pretty practical, straightforward, written for families and family‑friendly language.

See how it's being used now in Ohio. I'm always sort of waving the flag for these resources that feel so ‑‑ just practical and straightforward and helpful. Really helpful for families.

>> One of the outcomes of today's presentation, we hope you look at these tools and think about how you might incorporate them in your state as a resource. I just wanted to ‑‑ we just have a couple minutes left... and I want to just think for a minute about one of the bridges through the transitions in family's life is family to family support mechanism. Often... I know, for me, what it meant to transition from part C to part B... meant going from a model where I was part of the experience, of the intervention, itself, to putting my daughter on a bus and waving good‑bye while off she went to receive her, her education and so... transitions are often an emotional experience for families and the foundation of empowerment from the beginning is one that will serve families well through those years and we think about where we want to get to, not just the transition from what we talked about today, even part C to part B, but really, in the end, who we want our children to be and like I always say ‑‑ what we really want for our children is for them to pay their own cell phone bills.  
[laughter]  
 >> Of course, that's not totally the only thing, but... family involvement, empowerment, engagement in EHDI leads to skills needed in the future. You can go and look at the PowerPoint slides of some of the contents that are part of it and again... I think the role of parent to parent is one of those mechanisms, of those who have been through it before, can help think, help other families and thinking about some of the things that they need to think about and really, a lot of knowledge about what they need to know about going in to the next system.

I'm going to just close with a story, when I ‑‑ I don't know why this one came to my mind. I don't know if it really has anything to do with this, except I was thinking about all the things that I loved through the years as a parent... to moments of success in my daughter's life, so... I'm going to share one. We were standing in the kitchen and... my deaf daughter was standing with her hearing sister who was about eight months pregnant at the time and we were talking about the birth and the coming days ahead. I made a joke that, look, if we miss the birth, all right, but do not let them do the newborn hearing screening without us there. I just wanted to be part of that. And the birth...   
[laughter]

So... we were laughing and talking about what that would be and going into it ‑‑ and... my daughter, Danielle, the, our pregnant daughter at the time, turned and looked at her sister and said... man... wouldn't it be great if I had a deaf baby? You know... for me, that's one of the moments I treasure in my heart. It's a result of so many things in our own family journey that created a sensibility around the journey of deafness as being a positive thing. Of the fact that two sisters in a kitchen were communicating effectively to one another and we were all laughing at the jokes that, that that was there, that my daughter, to this day, the foundations that lead in the very first moments of identification, all the way through the school years, to adulthood, have served. So... I just want to thank you for all the work that you do in the EHDI systems, because at the end of the day, they're still going to be impacting families 25, 30 years from now. Thank you for the time. I don't know if we have one minute left for questions? No... we're done. Thank you.   
[applause]

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