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EHDI 2019

ROOM: DaVinci A/B

EHDI/AzEIP/ASDB: PARTERNING TOGETHER

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>> Hello, everyone. My name is Michele. I want to introduce our ‑‑ hold on.

>> Turn it on.

>> And ‑‑ okay. So I'm pleased to introduce our topic for this afternoon. We're talking about EHDI, and AzEIP, and ASDB ‑‑ wait, can I get all of these letters right? ASDB. Collaborating early intervention, service coordinators, to support the EHDI 1‑3‑6 program. And take it away.

>> Good morning. My name is Fran Altmaier, and I'm from the Arizona Department of Health services, the office of newborn screening. And I oversee the follow‑up program for all of newborn screening, hearing and blood spot in Arizona.

>> And good morning. I'm Jenee Sisnroy. I'm the Part C coordinator in Arizona, so I oversee the individuals with disabilities, education act, the Part C of that, so I oversee the entire early intervention system in Arizona.

>> So thanks for joining us this morning. We're going to just talk about a conference that we put on last year where we brought together the early intervention program, the EHDI program, and the state Schools for the Deaf and Blind to teach early intervention service coordinators about the EHDI system and things that they would need to know to work with families with children of hearing difference. So you can see the goals for our session, we just want to make sure you're aware how to leverage stakeholder participation, how to educate service coordinators about the EHDI system and how to improve awareness of timely enrollment in early intervention services.

>> Yeah. And before we get started, we just wanted to kind of get a show of hands of who is within the part C system in their state?

Okay. And do we have any audiologist in here today? One audiologist. And what about EHDI coordinators or? Awesome.

>> Nice.

>> Did I miss anybody?

>> Family based. Nice.

>> And we also have ‑‑

>> (Speaking away from microphone)

>> Great.

>> So from the early childhood technical assistance center is the other audience member.

>> Okay.

>> So thank you.

>> Great. Well, thank you so much. We're really hoping today that you can take some pointers back to your state on how you can better collaborate within the early intervention system and EHDI.

>> So blast year it started as an idea. So Jenee and Annie and I, so from the EHDI program and the Part C program, we were just sort of brainstorming, what can we do? What can we do different? How can we really educate the early intervention community about what we were trying to work on. So we had a preliminary meeting together and talked about it. Then last year at the conference here at our state ‑‑ at our state meeting, we brought the topic up to the Arizona group at large to get some ideas. We shared the concept with all the stakeholders to see what their perceptions of a training like this might be. So there was excitement, and then there was hesitation. So I feel people were not sure where we were going or what direction, and so that's where the hesitation and then those of us that are really interested in change were excited because it brought a really good opportunity to share and break out of silos that we were working in and really try to truly collaborate doing together.

>> And I think that's an important thing to keep in mind is a lot of states right now and historically the early intervention system and EHDI system we hope are working collaboratively together, we know there are states, within our state, historically, there have been some silos within our system. So one initially and barrier that we have based in the past is that, within our state, Arizona early intervention program, we have contractors that provide team based early intervention systems on behalf of children that are eligible for AzEIP, so that would be service coordination, developmental instruction, occupational therapy, physical therapy, social work, psychology, and then when a child is eligible birth to three for the early intervention program, we have a interagency governmental agreement with Arizona Schools for the Deaf and Blind to provide services for any child who has a hearing impairment or a visual impairment. So they then will receive services for a teacher of the hearing‑impaired or a teacher of the visually impaired, but that would be through the Arizona schools for the deaf and blind.

How we have it set up through our IGA is that those teachers will become a part of the child early intervention team. So we have a really great team‑based approach to services but, historically, what we have noticed is that when we are working together, a lot of our contracted service coordinators and our contracted teams don't have the knowledge to really understand how to support a child with a hearing loss or a hearing difference.

So when we were having these conversations, our biggest goal was to come together and see how can we ensure that the rest of the child's team, not the team and that really has the knowledge of supporting a family with a child with a hearing difference, but the service coordinator that is that role defining in early ‑‑ in the individuals with disabilities education act.

How does that service coordinator gain the knowledge? Because we all know that service coordinators don't necessarily have the knowledge of how to support a child with a hearing difference and the family of a child with a hearing difference. So how do we ensure that we can finally break that barrier and provide them the education that they need? Because they don't come out of school with that education.

They have a caseload of maybe around 60 children, if we're lucky, so they have the large caseload, and it's very rare that they there a child with a hearing impairment or hearing difference on their caseload. So when they have a family with a child on their caseload with a hearing difference, they don't know the resources in their state to refer a child, to get those services that they need. So when we're having these conversations, we were met with a little bit of hesitancy, because some groups were worried that we were trying to take away some of those, historically some of those ‑‑ be the roles ‑‑

>> Roles.

>> ‑‑ that were given to previous partners but really what we wanted to do is just ensure the child's entire early intervention team was provided with the knowledge to support that entire family. Because a lot of these children have other delays or disabilities, not just a hearing impairment. So they may be getting speech services on their IFSP, they may also have a sensory delay and may have occupational therapy. So we wanted to ensure that the service coordinator can be looking out for those other concerns and ensure that they're appropriately referring the child and family to the resources available. So that's where we started.

>> Yeah. So we brought together our committee. We thought, who all needs to be part of the planning of this process? So myself, another partner in from the newborn screening program, Jenee and Annie from the Arizona Early Intervention program, Sherri Collins is the director for the Arizona Commission of Deaf and Gard‑of‑hearing, she was really excited to be part of the planning, we had Kathy and Sonia from our office for children with special healthcare needs bring in their perspective, and I'll share in a minute their value to our team, Lila, our EHDI coordinator, and Barb Schrag, who oversees the Arizona state for the Deaf and Blind Early Intervention Program.

So, you know, we talk about educating service coordinators. I was once a service coordinator. I spent 18 years serving children birth to three. But what I didn't know and didn't have the resources to, as part of putting together this training, was CART services. I didn't think about that because that wasn't in the forefront of my mind. But thankfully, the other members of the team knew, hey, we need CART services. I hadn't even budgeted for it. So our office for children of healthcare needs coordinated the CART services and paid for it so we could be sure to provide that.

But I think that's an example of how everybody working together really made it a successful program and showed how we need to reach out and make sure everybody knows what you need to do. So. Our goals for the training was that service coordinators would know who to contact at ASDB to provide the support and answer questions for them.

When I was at a service coordinator, I had those people and so I challenged everyone in the audience to make sure, don't leave today without knowing who to call if you have a question. I would have a family who would always say, I went and had, saw the audiologist, what does this mean? Well, I don't know, but let me ask my partner over at ASDB to help me read this and tell me, do which need to bring them into the team? And with young, turn over group of service coordinators in Arizona, we wanted to make sure that they had those connections too.

So that you can see that was our big challenge for everybody, find someone. So this is a list of topics we covered at our event, what's newborn screening and EHDI, the basics; cultural sensitivity; ASDB services is; EHDI and AzEIP forms; resources; audiology 101, that was a huge one; OAE hearing screenings, how to access and provide OAE screenings as part of their evaluation and eligibility process; and then how to help families transition to preschool successfully.

>> And ‑‑

>> Go ahead.

>> I'll jump in real quick.

>> Yeah.

>> And just say it was really imperative for us to work together collaboratively and have the buy‑in and the support and the collaboration and coordination across all of the agencies that we had mentioned because without that, we would not have had the successful training that we had. We ended up having all of our early intervention service coordinators across the state attend because we made this a mandatory training. So we have the ability, within our contracts for our early intervention providers, to make our trainings mandatory, if we see a need that arises in our state. So we definitely saw a need that our service coordinators were not ‑‑ they did not have the resources they needed to support these families, so we made this a mandatory training and we had over 200 attendee in this training. So this was our definitely our most well ‑‑

>> Well attended.

>> Well attended training in early intervention, and we ‑‑

>> Oh, go ahead.

>> I was going to say, to put it in perspective, we started with budget planning for about 50 participants. We thought that was like really reaching to say we want at least 50 service coordinators to do it. We put out the save the date and the initial registration, we hit 50 in the first hour registrants. And we were like oh, my gosh, all right, let's go back and look, what can we do, where can we find more money, so we found more money and we bumped it to a hundred. Well, that didn't take very long and we were already at 100, and we were like holy cow.

One of the things that I think helped potentially is we offered for a ‑‑ it was a statewide training, and Arizona is a really big state with a lot of rural areas, we offered an incentive, we included in our budget hotel accommodations for those traveling from far distances, we had it start later in the morning so they could come, attend all day, stay overnight, and go home the next day. Some of the early intervention ‑‑ early vicinity intervention service coordinators work on billable hours, so we included a stipend that if they were attending and not going to be compensated and able to bill their agency to come, we would provide them a small stipend so that they could come.

We tried to really brainstorm any barrier that would prevent a service coordinator from attending and make it accessible to everybody, and so I think that's how, you know, by offering these things, we were able to get such a big turn out to our conference. So there, you can see a picture of the conference center and how many people attended.

So I think we can just go over a little bit about the schedule and the presentation that is we provided, you know, we started with the basics of the EHDI 1‑3‑6. What is it? We all know what it, is and having been a service coordinator, I knew we always asked did you pass the newborn hearing screening as part of the assessment, but what does it mean and where does it fit in the system? So we wanted to make sure that the service coordinators understood where that information comes from and why it was important.

>> Yeah. And what I have heard from a service coordinator before, she shared with me after this training about this specific portion of the training, she said, thank you, because when she would ask a family, we have a hearing screening tracking form that every service coordinator must fill it out, when they fill it out and they must ask a family if they passed the newborn hearing screening, or newborn hearing screening, and they say no, she looks at them like a deer in the headlights, like, I don't know what to do with that. Where do I go? And she doesn't really, other than data collection, she's collecting data on a form and she's putting in the row information on the form of follow‑up with an audiologist within six months, she never knew how to support that family. So this was very, very impactful for her.

>> And you can see there the survey results of what the participants thought of a overall rating of the session, and you can see that they really felt like they got something out of it. The next session was cultural sensitivity, use of the word hearing loss was I think a very powerful presentation that I think Sherri from the commission presented, you know, how to not use the word hearing‑impaired which is seems to be so common but really to start steering people away from that and using appropriate terminology, to give a really ‑‑ it was a very powerful presentation, and I think it was valuable to the participants. There's Sherri giving her presentation there.

>> And one thing that we have taken from this is just knowing that the word hearing‑impaired, several people within the community take that negatively, so we have been in early intervention and Annie is sit right here, she's our data manager, we have been taking that back and we are actually now updating all of our forms to reflect that. So we are using more culturally appropriate language within our early intervention forms to reflect that. So we're not looking as deficit based. We're looking more strengths based and putting that language in our forms.

>> (Speaking away from microphone)

>> Right. Right.

>> And I heard you say hearing difference earlier, and hearing levels or hearing difference.

>> Right. Yeah. And so that was, I think, the ‑‑ not, you know, over things you can use instead of hearing loss, people who are deaf or hard‑of‑hearing, hearing differences, different levels of hearing, threshold of hearings.

>> Yes.

>> Those are the things that we were reenforcing, and you can see through our, even our presentation now, we're still getting used to using the appropriate terminology. And it is being transparent that we're willing and willing to learn and continuing to just promote that message. I think that's valuable.

>> Absolutely.

>> I misunderstood what you were saying. You used hearing loss and ‑‑

>> No. Absolutely.

>> Instead of hearing loss, these are the recommended ways to ‑‑

>> Yeah.

>> To talk about a person.

>> Absolutely. And I'm trying my best to use hearing differences. That's what I'm most comfortable saying. But I occasionally let it slip and say hearing loss.

>> Yeah.

>> I did get my bachelor's in speech and hearing sciences, so it is very engrained in me to say hearing‑impaired or hearing loss. So I'm definitely working on it.

>> It's a work in progress, yeah.

>> But this has been very insightful. So we ‑‑ we're very, very appreciative of this.

>> We have to go quickly, we're running out of time. It went so fast. The ASDB services, so the role of the teacher or deaf of or hard of hearing, services they provide, information about deaf mentor. We're talking about general service coordinators. So this may or may not be familiar to them. So we wanted to really validate the importance of bringing someone from ASDB as part of the team, and this is why you have to include them, and not as an afterthought, that they need to be there up‑front. The differences, you know, between ‑‑ or explained listening and spoken language support and what role they play on a IFSP team. And you can see the survey results from that session.

Forms. Funny, this was not the favorite topic because who likes to talk about forms? But Annie and I talked about using the hearing screening tracking form that we developed to report referral and IFSP date, it gave parent consent to share that information with EHDI because our Part C program and our EHDI program aren't in the same program. So we need parent consent to share information with each other. So you know, we shared the form and how to use it and how to capture that, that information on a IFSP, but you, you know, it wasn't a favorite session but it was a valuable session, and it was sort of ironically the basis of the whole training was to support using this form.

>> Yeah.

>> And but there was so much more rich information that was available to the participants.

>> And ‑‑

>> And you can see our consent form on there that we use and that it will soon be replaced by a formal data sharing agreement using the FERPA exceptions so we ENT won't have to get the parent consent to share all of the data.

>> It was definitely an eye‑opener for many service coordinators because there was such a lack of training on that topic. Yeah. Just a lack of training. They were not appropriately referring children that they were screening. We have OAEs that we've provided our service coordinators, screening service coordinators but not appropriately referring children over to the Department of Health services so.

>> You can see the big yellow neutral.

(Laughter)

>> Resources, this was a huge one. Is sharing resources with service coordinators. You know, I'm a social worker and a lot of service coordinators have that sort of background, so resources are always a big one, what can I get to bring back to the families that I support? So this was a huge one. And there's our exhibits to we had, the commission gave out bags full of resources and stuff for them to take back and absorb and share with their families. So you can see that one, the survey results were really positive.

The other one was audiology 101, let's talk the basics of the ear and how it works and what these things mean, and this one was probably the top rated session of the day for service coordinators.

>> Yeah, they really just need to understand how to appropriately address hearing as a part of every child's IFSP.

>> Mm‑hmm.

>> So this was absolutely the top rated because there was such a lack of understanding of the foundations of hearing. So ‑‑

>> Yep.

>> This was ‑‑

>> The next topic was how to obtain OAE hearing screening training so that every time member can use that as part of their assessment for all children coming in to early intervention services an specifically children that don't already have an identified hearing difference. These are for all of the other children to really make sure we're assessing and evaluating ‑‑ evaluating that for every child.

>> And the next one was transition to preschool. So all of the children within early intervention transition to preschool and we need to really ensure that we can provide families with examples on how to access potential services after three years old. So this was definitely well received because service coordinators are not aware of the resources after three years old for children who are ‑‑ who have hearing differences. So this was definitely well received. This was presented in collaboration of the Arizona Schools for the Deaf and Blind as well as one of our contracted early intervention providers. So we really, really are hopeful that that presentation can support families after early intervention.

>> And then this is just the survey results before and after the training, how comfortable were you supporting children and families before today and then after today's training? And you can see there's marked improvement.

The other thing is if you remember at the beginning, I said I challenged every ‑‑ oops ‑‑ every participant to connect with somebody, find somebody that you can call or talk to after this training to, if you have any questions on supporting a family, and so you can see, 96%, all but five of the participants, felt that they knew how to ‑‑ when to contact us or a person from the state schools of the deaf and blind to help them support a family.

>> And being somewhat uncomfortable or extremely uncomfortable decreased by 75% of our early intervention providers. So this ‑‑ this one training was so incredibly impactful for our EHDI program and our early intervention providers.

>> And then this last slide here is just a link, all of this information is available on our website, all the PowerPoint presentations from each presentation is uploaded. If you go to the EHDI conference site, we've uploaded this presentation, and each topic actually has a hyperlink to that presentation. So if you want to look at the details of each presentation, it's all on the newborn screening website in Arizona. So funding was provided by our CDC grant which is supporting the collaboration data integration between the programs. Any questions?

All right. Thank you.

(Applause)

>> Oh, sorry, I didn't see.

>> (Speaking away from microphone)

>> I think it was all of our experiences. I mean, having been, come from the early intervention community, I spent 18 years there before I moved over to the newborn screening program, and I really saw that your average service coordinator didn't know, and it was just that brainstorming, you know, it started we had a little extra money left towards the end of the year, what can we do to really promote education, around then it just grew because we all had these passionate ideas on what we could provide. And I think the biggest thing is the collaboration, is well we really made sure we had the right partners that were willing to help and share their expertise.

>> Yeah. And from the Part C perspective, because we have interagency, governmental agreement with Arizona schools for the deaf and blind and we have contracts on early intervention providers but we expect them to work collaboratively on a team supporting the children who are eligible for services. From a ‑‑ the best case scenario, that would work out perfectly. But it doesn't always work out perfectly. So we do hear on a very regular basis those times that it's not working out great, and we really, really are dedicated to ensuring every child and family is getting the best resources, the best supports, the best services, and to in order to meet their outcomes.

So we've been hearing over the past several of years that this is not a perfect situation. So we really did recognize that we needed to figure out what the root cause was, and kind of support it from the ground up. And this really was what we identified as being one of the root causes. We need to support our early intervention contractors to have the knowledge to first ‑‑ you know, they're the first point of contact of the families, and we need to wrap around Arizona schools of the deaf and blind to support them for them to be able to support their families for what they do best.

>> Oh, we're out of time.

>> Times up.

>> But we can chat off after.

>> Yeah.

>> If there are other questions, maybe they can meet with you outside.

>> Yeah. Yeah. Thank you.

>> Thank you.