ROUGH EDITED COPY

EHDI 2019

ROOM: DaVinci AB

Engaging Parents, Developing Leaders, Part 2

MARCH 5, 2019

REMOTE CART CAPTIONING PROVIDED BY:

ALTERNATIVE COMMUNICATION SERVICES, LLC

[www.CaptionFamily.com](http://www.captionfamily.com/)

\*  \*  \*  \*  \*

>> Okay. Good morning. My name is Erin Thompson and I'm a speech language pathologist and listening specialist with the Children's Cochlear Implant Center at UNC. And I am here to update some people, possibly, or introduce to others a big project that we have been working on at UNC.

I was lucky enough last year at EHDI to introduce our engaging parents task force, and I made a promise at the end of that presentation to come back this year, if I was accepted, to update people on what we have been able to do a year past the end of our task force. So that's what I'm here to do today. I am going to review what our ebb gauging parent task force is for those of you were not able to be in my presentation last year but then focus on updates on what has been going on.

Nope. Yep. Okay. So to understand why we started this task force, it would probably help for everyone to know our mission at the Children's Cochlear Implant Center at UNC. Our mission to maximize hearing access for optical communication potential and we feel like we can do that in four ways. One, to provide quality services to children and families regardless of their ability to pay, to empower parents to be their child's primary teacher and advocate, coach professionals on the skills and knowledge needed to work with children with hearing loss, and then to try to improve outcomes through research and chit cutting edge science. And really, the task force comes out of that second bullet, trying to empower parents. And I have not given up paper notes, so I won't do it yet.

Okay. So that's a little bit about our mission at the Cochlear implant center at UNC, but what is our need? Our need and our desire to improve outcomes for children who are deaf and hard‑of‑hearing and vulnerable populations. We know that one of the greatest challenges for children who are deaf or hard‑of‑hearing is to acquire age appropriate language to communicate. And as services and technology continue to improve, we know that there are greater potential for and improved outcomes ‑‑ no. Greater potential for improved outcomes for children with hearing loss to hopefully catch up to their hearing peers by the age of three.

We also know that with the 1‑3‑6 guidelines that more children are being identified fit ‑‑ identified by one month, fit by three months, and then in services by six months which is giving them a greater possibility of acquiring those language skills to be at the same level as their hearing peers.

We also know from research that there are four main factors that impact outcomes. Age of the amplification, cognition, maternal education, around socioeconomic status. Therefore, children with hearing loss born in to poverty and in those vulnerable situations are at a greater disadvantage for catching up to their hearing peers.

So we asked ourselves, how can we better engage families to increase outcomes?

And the University of North Carolina Chapel Hill, awarded a junior faculty development grant to our director Hanna Eskrag to fund this project, and we used the engaging parents, developing leaders self‑assessment and planning tool from the Annie Casey Foundation.

Here is our lovely task force.

We recruited families based on SES maternal education, and diversity. We had two single parents participate, we had one set of grandparents as parents and we had one bilingual parent. Then we had staff participate, and we had one audiologist, one speech pathology, myself, and then our task force coordinator who was also a speech pathologist.

We were able to include graduate students in this task force, and we had two speech pathology students from UNC and one audiology doctoral student from UNC who had previous experience working with vulnerable populations. Parents and students were paid a city City penned for their time and we met four half days, Saturdays, over the course of 2017. We were able to provide child care and we did provide them breakfast. A lot of them were driving to meet us so we tried to accommodate some of that.

So the self‑assessment from the Annie E. Casey Foundation covered four different domains, building a culture of respect, inclusion and equity, coaching parents on competence and confidence, and if you were in the session just before me with Janet, then she kind of talked about competence and confidence as well, listening to and forming partnerships with parents, and then partnering with other organizations to serve the whole family.

So each domain consisted of three different levels of questions. The first level were more of those entry level basic questions, and then levels two and three got in to even more in‑depth and more specific. So what we did was we visually, literally wrote them out on giant pieces of paper, and again, Janet talked about pronounce, we, that meant I, wrote them out on giant pieces behalf paper, so went around, broke in to groups, so parents didn't see staff watching out how they were ‑‑ oh, sorry ‑‑assessing us, and then we voted and kind of not really voted. We ranked and rated ourselves on things that was it something that we always did, was it something that we sometimes did, was it something that we never did as a clinic, or was it something that either the parents didn't know if we did or not, or was it something that the staff didn't know if it was a policy that we didn't know if we had that policy or not.

And then we calculated, and you can see the different results. And some of it, especially on this one this one, the don't know category, that's a lot of things, that's very eye opening, helps you really see, okay, we either need to share this better with families because it is something we are doing, or if it is policy related or something, we need to look into it, we need to figure out some of this. So it really gave us a lot of information.

So we took that and then we really kind of divided it up in to strengths and opportunities. So I just kind of listed one out for each domain. An area of strengthened in domain one was that that whole team, the whole task force felt like the staff listened to parents and caregivers and really identify and view them as unique individuals, an area of opportunity is that unfortunately our staff is not racially, culturally or linguistically diverse and representative of all of the families that we see.

Well, we don't have any job openings right now so it wasn't something we could just change. But we brainstormed as a group of how, what can we do since we aren't able to go hire a bunch of new people and it was talking about creating parent ambassadors for our program that were racially, culturally and linguistically diverse and did represent all of the families that we see.

Then there were always suggested ideas from the Annie E Casey self‑assessment, there was a tool that went with it. So then we would go through and see which of the ideas from the tool fit with the ideas we brainstormed and the areas for growth that we had identified.

Here you see domain main two and the different scores for the different levels. Here, there's a lot more don't knows which was great. But then if you look at the sometimes category, there's a lot of things we're doing sometimes but how could we be more consistent, how could we improve on those things.

So domain two, an area of strength is that we provide training for caregivers on parenting and child development, and get very confident on that as something we do in all of our therapy sessions, our parent sessions, and really do in a lot of audiology mapping appointments now, especially with our cotreat model. An area of opportunity was to encourage parents to design their own work shots or events, and then we actually, as a group, brainstormed what kinds of things could we do as a group, what kinds of things could we have parents lead workshops on.

And the tool really encouraged the professionals to move away from being the owners of information because we're really not. And we have so many parents that could really make some connections with other parents.

Domain three, again, you see the split there and all of the different information we were able to gather.

And then our strengths and priorities. An area ‑‑ oh. Okay. I'm on the right an area of strength was, for opportunities for parents to be able to connect and talk to organizational leaders and to staff, we really tried to have an open door policy where parents can approach us wherever, and it was really nice to see that the staff and parents also felt that way. An area of opportunity was providing formal training for parents and caregivers to become those community leaders. Then the group brainstormed, trying to develop a program for parent leadership.

And then there was actually a link in the tool about how to do that.

I do main four, the final one, again, you see the split, again, sometimes was very high, that tended to be the dominant category which is good, but, again, how can we grow? How can we be even better?

Our main strength in this category was family level data records and in to tracking outcomes, and if you think back to our mission, that fourth bullet was research and cutting edge science and so we really are trying to track data, collect information for those research purposes. So it was nice to see that that was a strength.

Area of opportunity, trying to figure out how to collaborate more with other organizations, including some shared intake forms, how to provide different types of services in one location. And then we brainstormed. And it was such a big topic because frustration from families when they were sharing their stories was about having to share their story with every different organization and fill out the same forms over and over and over again, and wouldn't it be nice if we could streamline that and have it filled out one time, the parents were really excited and we were like oh, how in the world are we going to do this? But we know it's a priority.

And then some possibilities from the tool was to conduct a survey to see how other organizations in other areas of the community are potentially working together. If we don't need to reinvent the wheel, let's not.

So then we take all of this information that we collected and identify what our top priorities were. And we did that through a process called mind ‑‑ oops. Mind mapping. Where, again, took all of our paper, got it very visually oriented and organized, and we collected things, maybe there was some questions or areas of opportunity from domain one and domain four that we felt like went together. So we were able to able to visually put those things together and then we went around with our stickers again and we voted what our stop priorities were. So staff voted for theirs, parents voted for theirs, we calculated, and we developed our tier one and tier two intentions. So the thing that really rose to the top was the parent peer one‑on‑one parent coaching and collaborating and those connections.

Another one that was really important to the whole team was creating some sort of parent to parent social media group like Facebook. Figuring out a way to focus on family stories and family strengths. Then training action, training staff on available community resources. And then training parents on community resources.

A tier two intentions and priorities takes a little bit of a turn there at the top where you can see where it is more staff development, how can we really develop the staff even more, things like poverty simulation training, chronic stress training, cultural sensitivity training. Then there's a couple on here specifically think‑posium and opening doors workshop. Those are two UNC programs that UNC offer specifically.

And then looking at how to create parent ambassadors for our program. Then researching what other parent organizations are doing and developing resources for parents and parent led trainings. So that was kind of where my talk ended last year. It was like great, we have all of this information. It was great. Parent task force was a success, gave us tons of things that we learned a ton. But where are we now? What have we ‑‑ how have we taken those priorities and put them in to action? How do we hold ourselves accountable after I told everyone at EHDI last year that I would come back with updates?

So I tried to work back with our tier 1 intention, so you see, it was based off of what we learned from our task force. So that one that rose all the way to the top, those parent piers, parent connections, one‑on‑one. Gosh, I'm really sorry. One‑on‑one connections. And I'm really excited to share with you all about a it's a pilot program, really, of and we're collaborating are EHDI to our parents as collaborative leaders and workshop and modules. We are, as a pilot program, because it is being conducted on‑line for the very first time. These are parent training modules that EHDI has been putting on for awhile. But we are doing it for the first time through a program called WebEx, and we have eight families that we invited to participate as kind of a trial to see how this would work and if it would work. So we have eight families that are joining from across North Carolina. They meet one meeting a month. From home, join on‑line. And we ask these families that participate encompass in and kind of represent different areas of our clinic. We tried to do linguistically different, culturally different, maybe they have a little one that's been adopted with hearing loss, maybe they home school their child with hearing loss, maybe it is hearing aids, maybe it is multiple disabilities. We try ‑‑ we have a dad, we have a grandparent, you know, we tried to really have a variety of parents and caregivers participate.

They met in January for the first time to do a get to know you, share their stories, work out the technology bugs. But then just last week they were able and launched the first module, parents as leaders. So here are the ‑‑ and they're going to meet, there's ten different modules. So they will meet once a month from now through November. And you can see the different topics here that will be covered.

Well, there's supposed to be a photo in there. It's not there. There was a lovely photo that just showed kind of how the setup was, with the PowerPoint and all of the different families across the top, just to show the WebEx setup.

So then working on that second priority in the tier 1, that Facebook group. So we had had a clinic Facebook group at the children's cochlear implant center at UNC, I'm not even sure how long, several years. But that is for staff, it's for companies, it's for professionals, it's for everybody. And we really found that during our task force meetings, wanted somewhere for just them, where they might not be professionals commenting or reading or watching. So we are ‑‑ we were excited to be able to launch the families of the Children's Cochlear Implant Center Facebook page. So this is just for families. It is a closed group. We do have a couple of staff members that have to be ‑‑ have to participate because someone has to accept the families into the group. And another parent is not going to know all of our families.

We have, just the other day, we had 178 parents and caregivers that were a part of our group. And we just accept celebrated our one year anniversary, we got a big notice on Facebook that we had our first anniversary. And it has been really, we've heard from some families that they love it. They are asking each other questions, they're celebrating victories and milestones and sharing photos. So it has been ‑‑ seems to have been a great success. And it's not just for our families with kids with cochlear implants but families of children with hearing aids as well.

Then kind of changing gears just a little bit again and back to that staff development piece that was a big priority, so Melissa Octor, an audiologist with our clinic, and the Lillian Henderson, one of our speech pathologists went and took a seminar on crucial conversations and it is based off of this book. And they came back to our clinic and did a inservice for the rest of the staff, just helping us determine, what makes the conversation crucial? How to identify strong emotions, what makes it high stakes? And we had a great conversation about maybe things that the staff had experienced or how to use that between staff and with families.

And then we also went through some implicit bias training. And some of you may ask, what is implicit bias? Implicit bias refers to the attitudes or stereotypes that affect our understanding, actions and decisions in a unconscious manner. So we had Laurie Ray who is a consultant with North Carolina Department of Public Instruction and also an associate professor at UNC Chappal Hill, she came and did a inservice with our whole team. We took, as a ‑‑ not as a group, individually, before the meeting, we took an implicit bias test on‑line, and we, I think there were several different versions but we took the one on disabilities. And then we met as a group, talked about findings, talked about thoughts and feelings about that. And then we all picked a professional goal and actually met with our director to add that to our staff development plan. Because it's going to be a different goal for everyone and it's going to mean something different to everyone.

So where do we grow next in the area of self‑development? Because we know that's not enough, that's a great start, but it is not enough. So the staff members on our task force are still working on it. We are going through all of the options out interest for different trainings, UNC offers a lot of opportunities through their learning management system, and then through their Linda portal with ITS, the information technology services. And then also the Annie E. Casey foundation still has a lot of ideas. So the staff has kind of broken up in to in taking, researching and taking some trainings on our own and then going to meet back together and decide what seems like the best fit for our clinic and have the rest of the staff participate.

Okay. And then developing resources for parents, digital or other. So we're really excited about a resource that Hanna worked on to develop something that came up a lot in the conversations during the task force where about how confusing those early days of diagnosis were for families, who is calling me? Who does what? Why is the state the coming out, you know, what have I done wrong, you know, this was a common theme. And we know and we hope or asked ourselves if families know who is calling and why, do ‑‑ will they, will that empower them, will that increase follow through, would it increase poll call backs, would it increase services established, and could that impact outcomes? Well, we really hope so. So this postcard is now being handed out to all families, once they receive a diagnosis and when they are referred to early learning sensory support, beginnings, and the CDSA. So we're really hoping that this will help answer some of those questions in very family friendly language going forward.

And then last but not least, going back to that very first priority, that parent to parent, parent connections, parent leaders, we are in direct collaboration with the care project and Johnny Sexton to develop an app to help connect families. So think dating app but not for dating. There will be several types of families on there. So we would have mentor families, potentially those families that are going through the collaborative leaders modules, and they can put pictures of their family, tell their story, have that available. And then when a newborn family has a diagnosis or wants to make a connection with a family, they can log in and look through these files and look through these family stories to see which resonates with them and who they would like to connect with. I know that that's something we've tried to do at our center for years is to connect families and who have a common bond or a common piece of information or a common factor, but that's something we're choosing to connect them based on. That might not be what that family sees as their priority or the thing that is most important to connect with another family on. So this gives the freedom to these families to connect to what is important to them.

Maybe it's not the cause of hearing loss that they want to connect on. Maybe it is the age of diagnosis or maybe it's the location in the state or the country that they live in. Or maybe it is something completely different that we would not think of. So this would give them that ability. This app will also have some other features. It's growing. But it is in the works. Logos are being sent around last week trying to figure things out. So it is in the works, so stay tuned. It is also not just for UNC families. This is something that will be available to all families all across the country. And so yeah.

>> (Speaking away from microphone)

>> Well, that's a good question. So we will hope, my guess is that we will try to share publically on social media, we will try to share at different events. Johnny Sexton with the care project is everywhere all the time. And I'm sure it will be shared that way. So that's a good thing, though, we have to figure out how we're going to get it out there. Hopefully I'll be back next year.

(Laughter)

>> Update on how we're sharing the app. So resources. Thank you all so much.

(Applause)

>> I think I got in with like seconds to go.