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NCHAM-Family Support: Proof is in the Data

July 27, 2021

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~~Live Captioner standing by...

>> Family support proof is in the data, we will be starting that webinar in about 20 minutes.

>> Everybody that is presenting today, please just go ahead and call back in. Upon I don't know what the issue with that is. Hopefully that doesn't happen once the webinar starts. If it does, now we know we just have to call back in. Hopefully that doesn't happen again.

>>

~~Live Captioner standing by...

>> We will get started in about 8 minutes.

>> Okay. We are going to get started in just a few minutes.

I'm just doing an audio sound check right now. We just went through the presenters to make sure we could hear everyone. You should be hearing audio now. If you're not receiving a strong signal, adjust the volume settings on your computer or headset and then if you're still having issues -- .

>> Can you let me know if you're hearing me?

>> Yes, Daniel, I can hear you.

>> If you don't have audio, you might have to sign off Adobe Connect and come back in and hopefully you'll come back in with a stronger connection. If you still are having challenges, please

contact Daniel. His number is on the screen at (435)760-9049.

I will do one more audio check in about another minute.

>> Good morning or afternoon. We are happy to have you join the webinar today. We will be starting in just a few minutes. You should be hearing audio at this point. If you're not hearing audio, you may need to sign off of Adobe Connect and come back in and hopefully when you come back in, you'll have a stronger connection. If you're still having challenges, go ahead and contact Daniel for some technical support. His number is listed on the screen right now at (435)760-9049. You can either call or text him.

While we are waiting to get started, we just have a polling question for you. We are curious what your primary role is that brings you to today's webinar.

You may need to scroll down on the polling options.

Looks like we have a good mix of parents and EHDI staff and family-based organizations. A few "other."

I want to go ahead and close that. Then we are going to go ahead and get started.

Okay. Welcome everyone! If you are joining us for the webinar: Family support, proof is in the data, you are in the right place. The question and answers for the webinar will be at the end of the webinar after all our presenters have presented their material and then we will open up the webinar for questions. It will be in the form of a chatbox over on the left-hand side of the screen. I also want to point you to some files that we have uploaded and you can download from Adobe Connect just over on the left-hand side of your screen in the bottom. One is definitions that we've developed with this project. The other is a data tracking tool. And then we've also uploaded a PDF of today's slides. If you need technical assistance or need to contact anybody during the webinar, the pod over on the left-hand side of the screen is scrollable so there's additional information toward the bottom of that pod. So if you still need to contact somebody, their number and email will still be displayed throughout the webinar. If you do need to access captioning, you need to click on the CC at the top of the screen and select "show captions.." I'm going to go ahead and introduce myself really quickly. My name is Alyson Ward and I'm one of the staff members at NCHAM and we have the EHDI NTRC grant and I'm going to go ahead and turn the time over to Vicki Hunting who's going to be facilitating this webinar.

>> Vicki: Hi, everybody. Welcome, as the PowerPoint gets

put up, I want to welcome you and thank you for coming can today. We know that you have lots of obligations on your time and we're glad you were able to carve out this time for us. We're pleased to be able to share this work with you about what we learned when we did a deep dive into what it means to enroll families in family-to-family support. Today we are going to talk about -- we did the welcome and we'll do introductions. My name is Vicki Hunting, I'm from Hands & Voices, family leadership and language and learning, the FL3 Center. We'll have introductions from our panelists in just a moment and then we'll begin to share our learning from our work in the family EHDI data project or FEHDI as we've come to call it and the learning community. We'll talk a little bit about QI usage in this work. We'll share the tools that have been created and you'll hear from our panel about their learning in this work. And then we'll wrap up with some next steps and some Q&A. So now I'd like our panel members to introduce themselves. If Brandt, if you would kick us off?

>> Brandt: Sure, hi everybody. Thank you for joining us. My name is Brandt Culpepper and I'm a pediatric audiologist and the Georgia EHDI coordinator. Richard?

>> Hi there, my name is Richard Wentworth and I'm family outreach specialist with the Massachusetts newborn hearing screening program and I am also the parent of a 14 year old boy named Henry who has reduced hearing and is in fact graduating from middle school today.

Big day for all of us.

--

>> Suzanne, do you want to go next?

>> Yes, this is Suzanne Foley, I'm a clinical pediatric audiologist and also the director of the Indiana EHDI program.

And Amanda is next.

>> Hi, I'm Amanda Hvass, and I live in Oregon and I work for Hands & Voices and their good by your side program as their coordinator. And I have a 12 year old tomorrow Deaf boy that I have been raising and that's who brought me here.

>> Thank you, Amanda, and thank you, panelists. So if we start at the very beginning of this work and we think back to when the original HRSA, the notice of funding opportunity or we call it the NOFO was released in July 2019, this program objective served as the basis for the F EHDI working group and that program objective is to increase by 20% from baseline the number of families enrolled

in family-to-family support services by no later than six months of age.

So it began with a conversation that took place during the EHDI conference in Kansas City in 2020. During the EHDI coordinator and joint family-based organization meeting. It came from a need and a want to work on this program objective together with those that would be gathering the data for reporting. The EHDI coordinators and program staff and family-based organizations and parent partners. And from May 2020 through March 2021, almost a year, a group of EHDI coordinators and parent partners began meeting two times a month to begin tracking the discussion on the impact of this enrollment of families into family-to-family support.

The purpose of this working group was to create a draft of definitions for this particular EHDI program objective that was outlined by HRSA. This work included identifying data that the EHDI programs needed to monitor this enrollment in family support so they can report progress on the objective to HRSA. It also included specific data needed by family-based support organizations or family-based organizations, or FBOs, to be able to provide data to EHDI programs on the work they are doing to support families. In some EHDI programs, this support is provided in-house by EHDI parent staff and not provided by other organizations.

In addition, a data entry form was also created to assist in pulling data from the EHDI systems by child to track specific items for this measure, understanding that this data may change or vary depending on when data was pulled and birth date range. And the parents and caregivers can ry engage at any time on this journey. Standard data collection across EHDI programs is vital to improving the EHDI system and meeting the needs of families we serve.

We started with the HRSA measure and for a couple of months discussions centered around the data that we thought we would need to report on this measure. And we began to document our notes and definitions based on what the current processes and procedures looked like for each of these original four programs.

And then consistently used the HRSA objective measure as our filter to stay on task. We looked at terminology and parameters that were familiar to us and already in use under the standard EHDI 136 guidelines, like referred or enrolled, declined, the types of contacts made, et cetera. We considered definitions and terms already being used by HRSA and CDC. Early on, we were also

looking at what fields and FBO, or family-based organization, might need to follow the family and provide supports and services to family beyond diagnosis and enrollment.

Fields like parent and provider names and contact information, dates for enrollment into Part C or early intervention, screening and diagnosis, amplification information, language spoken in the home; but ultimately a lot of those fields were determined to be out of scope for this particular work. That doesn't mean that those data points were not important to ensuring families get what they need when they need it; it just meant that those kinds of fields were outside the parameters of this specific program objective measure and in themselves could be an entire project.

The original F EHDI team included an EHDI coordinator and parent representative from these four states. This group worked together closely for almost a year to come to the draft of the document tool that we created and we'll talk about in a few minutes.

Brandt Culpepper from Georgia and Amanda Hvass from Oregon are on the call today and will be sharing further with us about their experiences.

Once the original F EHDI group created the tools and wrapped up the work we started out to do, the NTRC and the FL3 Center gathered another group of EHDI coordinators and parent partners for a learning community to pilot the work that began with the original group. So you'll hear from some of them in a little bit about their learning. Suzanne goalie from Indiana and Richard Wentworth from Massachusetts. It was also important to us to use and apply the model for quality improvement methodology to our work and discussion. So a brief primer on the model for improvement. The model has two parts. The three fundamental questions at the top, and the plan, do, study act, or PDSA cycles that guide the changes and help determine if the change is an improvement. First of all, what are we trying to accomplish? What is our aim or goal? Our aim helps us to clarify what we are trying to accomplish and creates a shared, common language to communicate to others about our work. In the second question, we get to measurement: How will we know a change is an improvement? This helps us tell the improvement story and helps us to know whether the changes we are making are actually leading to improvement.

Measurement doesn't have to be complicated and we use it

in different ways so that we can get the complete picture.

In the third question: What change can we make that will result in an improvement, this is where we discuss and brainstorm ideas that we have about changes we can test to accomplish our aim. Ideas for change come from several places, from insights and experiences you have gained doing the work that you do every day working in the system. They can come from creative thinking or brainstorming with others or by borrowing from the experience of others who have successfully improved.

The changes then undergo a loop or PDSA cycle that helps you make a plan for the change, do the change or test it, study if the change is working, and then act by making a decision on how to move forward.

For this learning community work we crafted this is our aim statement. By July 31, 2021, the seven EHDI programs that are participating in the F EHDI data learning community will have the capacity to track and report on the 2020 HRSA objective to increase by 20% from year one baseline the number of families enrolled in family-to-family support by no later than six months of age.

We will accomplish this by working to understand, by understanding and using the operational definitions that were created by the original FEHDI, by using the FEHDI data tracking tool or some other tracking mechanism, and by deploying the peer-to-peer learning to build confidence and capacity in reporting this enrollment into family-to-family support by no later than six months of age.

So I know that you can't read this. It was intended as a visual for discussion. This is the definitions document, the tool that was created by the original FEHDI group and then reviewed again by the learning community team. It is available for download for you here today if you have not seen that. This draft document has not been edited since finalization in December of 2020. So we just wanted you to know that that was available and share that with you today if you have not seen it.

Again, this is not intended to -- seen as a visual, this is an Excel file tool created to allow programs to attempt to add child specific data and to practice the data needed that is necessary to report on this measure. In a few minutes you will hear from our panelists about how they used this to test what they needed to meet the program objective. Some states used it as is, some states

modified it for their use, some states used it to create standard reports in their EHDl data systems, and some states only used it to practice collecting the data needed as they already collected it similarly in their own system. The testing exercise helped them to determine where the data needed to come from to track the measure.

I'll pause for a moment. You can read these. You can also read them later in the PowerPoint. It's available for you to download.

But now we are going to move into the next part of our presentation so you can hear from those involved in this work about their experiences. We have a series of questions that they will respond to.

So that said, let's just jump right in on this first slide. Our panelists today are going to share for the slide their reactions to the FEHDI definitions, how they felt they were in alignment or not, and share challenges and opportunities that came up during this discussion. So Brandt, will you get us started, please?

>> Brandt: Sure. Thank you, Vicki. And as part of the original group, I think a lot of us were feeling a little befuddled as to how do we accurately collect the data on family-to-family support services that were offered. And the one that tricked us up the most was what is enrollment and how do we define that. By working with the other states and having both that EHDl coordinator and family perspective, it really allowed us to kind of calibrate within our group and make some of those determinations about how do you record this and what does count as family enrollment.

Before we got involved with this, we had a really good working relationship between our EHDl program and our Hands & Voices, which were in two separate agencies, so we are not housed in the same location. Even though we had that good working relationship, we hadn't really discussed in detail how we defined those different terms. Hands & Voices reported back to us on the numbers of families that they served through both the Guide By Your Side and the advocacy sport and training, the ASTRA program. We entered it into our tracking system but we didn't count that and we for sure didn't use that six-month target as a guideline for when that needed to happen.

So as we worked with this back and forth, we really found a number of opportunities that strengthened the ties and the collaborations between our two systems and we found that putting

some of these definitions that we came up with into practice with real cases allowed us to talk through some of those tricky situations for how do you record this in the database and does this one count or does one not count, that type of thing. And going through that process, I think, has really solidified the relationships we had and allowed us to improve the referrals back and forth between our programs and strengthened that offering of family-to-family support overall. We're seeing an increase in our numbers already. And with that, I'll hand it over to Richard.

>> Richard: Thanks, Brandt. You know, when you mention the enrollment definitions as being a bit tricky, we actually felt that as well. That was one of the jumping off points for us. It was really nice to come into this with a lot of that sort of foundation being laid.

Our initial reaction to the definitions was one of a lot of questions, a lot of questions came up, which is how we knew this was going to be meaty and good, a good process for us to go through. It immediately spurred conversations between our program and our team and our FBO partner, who is the Federation for children with special needs and their Family Ties program.

Looking at the way that we've collaborated with the Federation in the past, which is very close, it was actually -- it really showed a glaring spot where we didn't have a lot of information post referral to family support with them. We did not have a lot of information on exactly what happens to families through that part of the process. So for us it really did force us and encourage us and challenge us to have some really good conversations with our partners in that program to sort of start to shine a light on those parts of the process for us.

Suzanne?

>> Suzanne: Thank you. I do want to say that in Indiana we are very lucky that when our EHDI program was initiated, the integration -- support in our program was done in a way that makes it very easy for us to share data. And I don't take any credit for that. It was done when the EHDI program was started and we partner with Indiana Hands & Voices locally. Because of that, we have consistently shared a lot of the information that is in this workbook tool that we worked with as part of this group as far as the definitions and the data that was tracked. However, just going through this tool did, again, as all the other participants have said, did spur some great conversations with our family group, with Hands & Voices, to say maybe we need to take some time to

redefine some of our definitions, even though they have been this way for a while and we assume let's go through and say what does enrolled mean, is that -- if they are receiving ongoing services, does that mean if we say we are going to follow-up in three months, and really took some time to define that for our purposes and for our policies. We also have the ability in our data system to track why families don't participate or if they at some point discontinued services such as moving out of state or deceased or their hearing was determined to be normal. So we have been able to track that, but I think there were so many data points in this tool that allowed us to review what we are currently collecting and then make some better policy decisions about what that means. We also discussed at length about closed files, meaning our goal is to provide parent-to-parent support for a year and we close the file in a year, but are we making sure that that service is discontinued, not in a way to not support the families but to possibly improve them engaging in the organizations in our state instead of the one-on-one parent support. Again, just like everyone mentioned, I think it was a great review and a great way to start those conversations and possibly clarify what we have been doing already.

Amanda?

>> Amanda: Thanks, this is Amanda. For our state, the initial reactions to the definitions, it was really, really interesting to go through all the different types of contacts. In Oregon we have got Hands & Voices and the Guide By Your Side program, Hands & Voices has a contract with EHDI and we're able to use their database which is fabulous and so great. So we have been tracking data pretty well but an area that we realized could use some more looking at was when we would get ahold of a family but then we couldn't connect with them again. Because we have an opt out system here, like we would have just counted that as someone within our program, but maybe we've only talked to them once and not for six to 12 to 18 months. So really looking at what enrollment looks like, this has been a really great tool to really actually -- .

Our quality improvement and what's in Oregon, with having more contact with the families and then defining how much contact. So had some really great conversations about what it looks like to support a family once they're enrolled and what keeps them enrolled.

>> Thank you, Amanda. Thank you, panelists. for the next

questions, we are going to ask them to share about the tracking tool, maybe how it was different or the same from the way they tracked this data from before and what their future tracking might look like based on this work. So Brandt, will you kick us off?

>> Brandt: Sure. Before we started this process, we were sharing data back and forth, but we weren't really tracking baby by baby and we weren't looking at family engagement by birth cohort. We were just reaching out with our contract, we had Hands & Voices providing that family support and they were reporting back child specific data to us on all of the families that they served over that last month. So with this new way of doing it, we're more aligning it with the other data that we collect and report to our federal partners. And we are looking at it by birth cohort and adding that time frame with that six-month target in mind, which that's a tricky point for us. For some of those kids, they're identified later. In Georgia our audiologists report all newly identified permanent childhood hearing loss for kids five and under.

So our Hands & Voices chapter also receive those referrals and see a number of families beyond that six-month time frame that we are going to be reporting on those as well.

We did test the FEHDI tracking tool and we found it very useful in going through and reinforcing some of the information we were already collecting. The actual Excel spreadsheet that we're using, since we're using different databases, we do have to modify and we've had to add some fields because our database in EHDI uses a different unique identifier from the Hands & Voices database. So we've had to add a few fields to make sure that we're tracking the same kid and not duplicating services and that type of thing. But once we got that worked out, it's working very well.

One thing that has been very helpful in working through this process is EHDI is a very dynamic program, as everybody knows, and our Hands & Voices chapter is actually stepping out and becoming a little more independent. When we started our contract with them, they were working under the Georgia PINES, the parent infant network for educational services which is run through the Department of Education and they're stepping away from DOE and operating independently now. So once we realized that, okay, we are going to have to change databases, we already had the data definitions and we had this Excel spreadsheet that we could use and tweak just a little bit more to allow them to still receive that information and provide that continuity of services to families, even

though we are in transition.

We are planning on adding a couple of more elements to our EHDI database to better allow us to differentiate the kids that are in that initial EHDI phase versus that ongoing surveillance that a lot of us are looking at now. A lot of the reports that we have that are automated generated in our system capture everybody, so we're working to redefine some of those reports to separate EHDI from ongoing surveillance. And then since we have added some new fields, we need to work on generating some of those reports to make the data tracking a little bit easier for us.

I will hand it to Richard now.

>> Richard: Thanks, Brandt. So in Massachusetts we were tracking the conversations that I had with families. I would basically make notes about what I was going over with families. I would do direct referral to early intervention, but otherwise we would sort of go through the checklist of information that families need to know. And Mass Family Ties was one of those resources. So it was one of many things that I would simply keep track of that I would mention to the family, so really not tracking anything more than that. Not tracking a referral, not tracking what happens to the family after the referral. So we were very excited to start using the tracking tool, which we did. And one of the immediate benefits that it had for us was to get us just thinking about this resource, which again, was one of many that we were putting in front of families. It really helped me personally in my conversations with families to really kind of reignite the excitement around it and to be able to add it with my own family narrative, which as a parent of a child who is Deaf, we were very, very helped out initially and supported by other families and by connections to other families. So when I started to think about it that way, that immediately helped. Also, we decided we were going to be able to make direct referrals because of the discovery that they had a web portal, Family Ties has a web portal. These things immediately started to change the way that we were able to do things. And then to use the tracking tool to follow kids that I processed, again, this really helped us to focus our caregivers with Family Ties and with the Federation to understand what -- for them to understand what they could be helping us out with in terms of information. And then we were able to take that information and start to resculpt the way we enter in the data, that we capture this data in our own system. Thankfully in Massachusetts we have the support of an amazing epidemiologist

in our program, Martha Morris and also our database administrator, Dan Shue, who were able to immediately fold those data points into our collection methodology so that as I'm going through a call with a family, I can start to enter that stuff in right away. We also, as Brandt mentioned, we also have two different unique identifiers, one for our system and one for the Mass Family Ties system. So the challenge there has been to get as much information as we can to start loading into our system that we can then match up, but we also have a Memorandum of Understanding, a draft memorandum, being developed that will allow us to have a more solid data link up between our two programs. So yeah, it has had an immediate impact and has definitely shaped the way that we collect our data. I'm excited about what this means about how we are going to use this moving forward as well.

Suzanne?

>> Suzanne: We did use the tool. We added some of our data in just to see what other information it might give us. We have a big report that comes out of our EHDI data. We actually named it the big kahuna for some fun. Our IT support person can add different fields into that report. We also have the ability to pull a Guide By Your Side report with any of the data points that are in the system. So many of the data points in this tool were already in our system, but we do a little manual double check, our Guide By Your Side program keeps a separate spreadsheet on a little bit more information than we do in our data collection. so this was an opportunity for us to look at how to change our current data system to reflect these better. And one of the columns specifically that I really appreciated was when it would automatically calculate, for example, the age. There's a column that said, it took the data and translated the age of diagnosis, just based on putting in the date of diagnosis and subtracting it from the date of birth. These kind of manual calculations then allow us to filter a little better to see where are we not meeting our 136 goals. So we did ask our IT staff support person to, in our big kahuna to calculate some of those columns. So instead of us not having access to that information as quickly, could they just add those in with calculations. So that was definitely a benefit of the tracking tool that I think can be very helpful in terms of when you look at epidemiology and analyzing lots of follow-up and trying to target where we need to improve our efforts.

Amanda?

>> Amanda: Thank you. We have a really similar experience to that, Vanessa. In Oregon, like I mentioned, we already had a tracking system and a great database through a woman named May that works at Oregon EHDI and she's like a genius with these things. So we had a great tracking system like even before we did this FEHDI group, we could like click on little things within the database. When we would call a family, we had a whole little list of things we would be check marking as we went, like did we send a welcome packet and did we talk about the different modalities and are they enrolled in intervention. We had great things, if the phone call was an attempted phone call and we couldn't get ahold of them or did speak to a parent or left a voicemail. Those things were really dialed in. When we went to use the FEHDI tracking tool, it was really interesting to see what information was kind of lacking, like contacted but unresponsive, that was not one we had been tracking so much in the system. And then like I mentioned before, at what point do you consider it unresponsive? How many days or months? And then unable to contact, at what point do you consider them unable to contact? How long do you try for? Our opt system in Oregon, we love to give families every opportunity to get in touch with us at some point within that first three years and we'll make contacts at least like we try really hard for the first six months and if we just can't get ahold of them, we'll try to lightly get ahold of them for the next couple years. And that's a real service to the families just in case they're more open at that time. But how do you track that in the system? So the FEHDI tracking tool was really useful for just cleaning up and clarifying what it was looking like to be in contact with the families.

>> Thank you, Amanda. Thank you, panelists. In the next question, it's not EHDI work if we don't talk about QI, or quality improvement, so we are going to ask the panelists to talk about the quality improvement aspect of this. So Brandt?

>> Brandt: Thank you, Vicki. We have a number of things planned now that we are collecting additional data and we have a different way of looking at things. But simply by going through this process, I became very thankful that we had a contract in place that we could amend the data points that we were collecting and allow us to continue sharing that data back and forth. When we sat down and really took a look at what was happening, we found out that we'd made some assumptions in the referrals that EHDI was

making to Hands & Voices and we had some gaps in the program that were kind of filtering out some of the kids. So we have been able to fill in those gaps to ensure that we're providing a better standard of care to all of our families in Georgia. And then one thing that kind of surprised me that's just kind of anecdotal is that in going through and developing that shared definition and that shared understanding of what do you mean by this, our handoffs of communication are a lot more efficient now because we know what this term means and we know what that term means. So we're getting questions back and forth between what do you mean by this or what do I need to do with this case, because when you look at something on paper, you don't always have all of that information there and we know not everything fits in a little spreadsheet. But by having those shared definitions, I do think it's improving the efficacy of that communication back and forth. And we do have, as I said, a number of ongoing QI projects planned to take a look at which families are we not able to contact and why, and which families are accepting the services that are being offered and which are not participating.

Richard, you're next.

>> Richard: Thank you, Brandt. Yeah, we have our program has been no stranger to PDSAs and the Plan-Do-Study-Act cycle to the point where anytime a problem or challenge comes up, one of us always corrects to know it's a possibility. So utilizing it in this mode and this project really helped to break it down into lower pressure, manageable chunks. For instance, we immediately recognized that using a direct referral DME, in my conversation with the family, would immediately improve things. So well, let's try that, and there was no hesitation because we knew we would be able to track that on a smaller scale and see if it works. And it has worked amazingly and our numbers of referrals have shot way up. What I'm excited about is to continue that, continue to roll that QI based on the information that we are getting now. And I feel like we are just about into that next plan phase of the cycle where we can now build on the gains that we've just made as a result of the initial phase of this program.

Right now, we're getting a lot of families into Family Ties and getting a lot of families into this family-to-family support. So what's next? How can we even continue that further? We do a lot of things in Massachusetts auxiliary to that. We do events for families, we do Meet Ups, we do Facebook Live events. We have a lot of

ways that we foster community and one of the things that's been really exciting to see is some families that I'm getting to very early in the process have said, I don't think I need support right now, but I'd love to help another family out. So we're seeing that. Having the pay it forward part of what Mass Family Ties does, in training the next crop of support parents, knowing that we're infusing that right now with "new blood" again is very exciting to think about where we can take this next and I think QI is going to be a big part of that. Suzanne?

>> Suzanne: Thank you. I do have to share that except if are our administrative assistant all of our staff, our follow-up coordinator, our two parent consultants and of course our Guide By Your Side and ASTRA coordinators are all parents of Deaf/Hard-of-Hearing children. I'm very fortunate that when you look at QI, I literally have to do nothing, that they are consistently looking at our program and trying to find ways to improve it, whether it's data collection, our software, what we send out to doctors, to families. So it's a unique situation in that, but what was helpful for me as a director is certainly just working as a staff member of the Department of Health here, we discuss a lot in big programs about QI and different what I call formal QI programs. All of our QI has been pretty informal, meaning based on our grant submissions and grant goals and what we are tracking as far as 136, but we've not actually utilized one of these types of formal QI programs. So in a brief way that this collaboration allowed us to do, it was very helpful to just watch a short video or look at a little review of them instead of doing a deep dive and trying to figure out are any of these QI procedures helpful, do we think that they would work for us. So I shared a lot of what we talked about in this as far as those different types of QI programs and the staff is going to pick one that we are going to use over the next year, because we're also -- we've never had a policy and procedure manual at EHDI. So that was one of my goals a few years ago when I started. So as we u that, we are going to be going through a more formalized process. So I think QI in general in terms of some of these formalized processes can be overwhelming to think about and not know which one to choose. And the information in here was just sort of a great short review to get us going to have a little more formalized process.

Amanda?

>> Amanda: This is Amanda. In Oregon we've done lots of QI different things, especially through use of the database. Like I

said, May is just a wizard at this. So we have been looking at data and reflecting on it and checking out how our program specifically can improve or what sort of partnerships we can make that would make a difference in the families and in our 136 goals. But something that came up just from this, like this just took a different angle, like different people sitting at the table from all over the nation. It was very helpful to get these collective thoughts to be able to look at where we can improve the program and our partnerships and our EHDI goals for the 136 goals. So a specific area that I personally found as a program coordinator was I know that EHDI tracks Oregon EHDI, tracks the 136 goals very well. But for me oftentimes I'm hearing about that and looking at it, but it really -- I try to make sure that we're making sure we get the referrals called within a specific amount of time and we have these program goals, but it really helped me look more specifically at the ages. And we talk about how kids are getting identified at a later age sometimes. So there's this reality of maybe not hitting the 136 goals but it was fascinating that as a program look to see can we make it go any faster so we do get those goals. Like I said, it's something I paid attention to before, but just having all of the different ages put into the Excel spreadsheet so well, like someone had mentioned before, those kinds of things just struck a chord in a good way, being able to look at things differently, so it was very, very helpful.

>> Thank you, Amanda, and thank you, panelists. As we're running out of time, as usually happens in cases like this, just our last question if our panelists would just speak briefly and talk about a take away from this work and what advice would they give their EHDI peers when they're looking at gathering and analyzing the data for enrolling in family support? Brandt?

>> Brandt: I think one of the biggest take-aways we have was we thought we had a really good system in place, but when we started peeling back the layers and really looking at the nitty gritty, obviously we found some areas that we could improve and we could just better offer services to families, and better communicate with our families and with each other. We certainly found a lot of opportunities within our data system to allow us to better track specific information rather than the aggregate generic. So we'll continue to provide that communication back and forth between our two programs as to what works well and what doesn't, with that ultimate goal of getting families what they need and making sure

that they're aware of the services that we do have available.

Richard?

>> Richard: Thanks, Brandt. I think the take away for us is we have so many great resources in Massachusetts with our programs. We have so many resources at our disposal. Even with that there was a large blind spot here. And we are now examining that and we are reinforcing it. So I think the positive to come out of that is that we now know that we can actually do this with some other parts of our program, with other areas, we can examine things a little more closely and see where else we can take this. It's really important not just to have the resources but to know where to look, where to focus them, and tools like this are very important and projects like this are very important. We're thrilled to have been included. Suzanne?

>> Suzanne: One piece of advice I would give to anyone struggling with this is, one, stay creative on ways to share data. I know many of us work under the umbrella of larger organizations. For example, we're under the Department of Health. Four years ago what we were told we couldn't do we can do now. So I think getting away from the well, we've never been able to share data with our family organization, therefore, we are not going to, or looking at ways to do MOUs or data sharing agreements. We initiated data sharing agreements with our WIC and DCS in the state. We were told three years ago we can't do it and I just keep asking and now we're doing it. I think being creative. Our Guide By Your Side and astra staff are employees of EHDI which allows data sharing. I think if any of your states are not communicating with your family organizations, that needs to be the first step in the process. Again, I know I'm speaking from a place of gratitude that we have a very strong state organization, but I have learned as a clinical audiologist that one of the most critical pieces of this EHDI process is the parent support. So whatever you can do to engage the EHDI coordinators engage with those family organizations and keep working and asking and finding ways to share data is only going to benefit the kids that we serve.

Amanda?

>> Amanda: Thanks, Suzanne, this is Amanda. I'm going to piggyback off of that. I feel like one of the greatest things for our program and our EHDI system here, one of the greatest moments is like when we really established a great baseline of trust. So just like the human plug here for relationship and dignifying and having

integrity with one another as this can be a tricky thing because you are staring at numbers and you need them to be good in order for future funding and all the different things. So when you're looking at numbers, it can feel kind of intimidating if you're not doing well. So just establishing, I would love to encourage everybody to build those good relationships with their FBOs and EHDI partners, because when you trust one another, you're able to be transparent and look at the numbers and call it what it is and say this is where we're at and then move forward from there. But that really happens in a safe environment of really valuing each partner and what Suzanne just said, the family partners can do something that the EHDI system cannot. And the EHDI system can do something that the family partners cannot. So just understanding that we really do well together in supporting one another and valuing each other in that can breed trust just from like being thankful and saying out loud what the other person is doing or what the other program is doing for the families. I feel like we really hit our stride after we started trusting one another more.

That's my encouragement.

>> Thank you, Amanda, and thank you to the panelists for sharing your insights and experiences and expertise in this work. I'd like to thank all the participants from the original EHDI group as well as all the learning participants for their time and dedication in walking through this with us. Going forward, the tools that we shared today will be housed electronically and that will be communicated to everyone soon. There are notes to edit the current content for either of the tools.

Finally, we'll continue to spread our learning at EHDI 22. Keep your eyes out for a possible instructional session and work to continue these discussions with our federal partners, with HRSA and CDC. In the PowerPoint our contact information, and again, thank you. We appreciate your time and now I'll pass it to Alyson, if you have questions.

>> Alyson: Yeah, so I did open up the Q&A box over on the left-hand side on the screen. Go ahead and type your questions in there and I will field them to the presenters. So the first question that rolled in is for coordinator, so for Suzanne and Brandt. How have you seen this work impact the development of parent leaders in your system?

>> Brandt: One thing I've really seen is we have some very strong parent leaders that have been in our Hands & Voices

program for quite a while. But I think just from my perception, I wish taShawnda was here to tell you how she feels about this, but I think coming together and working through this process with everybody at the table and everybody has an equal say and an equal chair, I think it has given them the understanding that we do value the input and the services that they're offering are so incredibly important to our families and the information that's heard from families is so different, I think they understand that we appreciate their efforts and that we really do need them. They need us and we need them.

I'll stop there because I could go on for a long time.

>> Thanks, Brandt. Suzanne, do you have anything to add to that?

>> Suzanne: I was going to say as an EHDI coordinator you can utilize parents in many roles. We have several parents who work full-time and can't take on the role of a parent guide but want to be involved. So I have invited them to do parent panels for some of our graduate students in audiology. We've videotaped several of them to use in our training to hospitals. So I think having the EHDI coordinators not be afraid to integrate parents in some of that, even on your advisory boards. We have parents on our advisory board that have not been a parent guide just to give their outside opinions and impressions. I think that develops parent leaders because as we all know, most parent leaders are there because somebody asked them to participate. I think EHDI coordinators have a role in that that can be helpful.

>> Great. Thank you, Suzanne. So the next question is for Amanda and Richard. How has your autonomy impacted the trust with EHDI stakeholders?

>> Amanda: Do you want to define a little bit more?

>> Yeah. I think that what was meant by the question is the autonomy that this project has allowed you to, in terms of figuring out definitions and so forth. Go ahead.

>> Amanda: Previously our program was housed within EHDI. So we in the last five, 10 years have really set ourselves outside of EHDI. Our program is no longer housed within them. So going from employees within the system to outside the system, that autonomy was also like a big step in a different direction, which was a good one. But then also this specific opportunity that we had here with FEHDI really just helped us almost even find a voice and even to find for ourselves what is important and how do we want to

serve families. So the quality improvement was great for the program itself, and obviously also affects EHDI as well. So yeah, I feel like it helped us define things even more. And some things were already in alignment. It was like, yeah, we already do all of that because that's something we care about, which was awesome, because it builds that trust that I was mentioning before too.

Richard?

>> Richard?

>> Richard: Yeah, my position is within the state EHDI program, so I am a parent within the system, so to speak. I'm part of a team, with Sarah Stone and Jennifer Flemming and the rest of our team. We come to a lot of decisions together about how we are going to pursue things, especially with this project, but ultimately in the conversations with families, I am calling the shots within there. So there's a larger framework in which it's an entirely team sport and then once we're in the call, it really is a parent-to-parent, family-to-family situation. And I bring the entirety of my situation and story to bear on that. It's a very powerful moment and it's only strengthened with getting a newfound access to this excitement about getting families more support.

Hope that answers that question.

>>

>> We are unfortunately out of time. There were a few questions we were not able to get to. I do want to highlight the contact information for all of our panelists today who all did an amazing job, both in participating in the original FEHDI group as well as the learning community and I know they would be more than happy to share additional ideas about their experiences and plans moving forward. So their contact is on the left-hand side of the screen. And then if you would please fill out the evaluation, if you click on the link on the hyperlink that says "click here," it will take you to a survey that gives us a little information on how helpful this webinar was for you today and we really value that type of feedback just in future planning and so forth. I'm going to go ahead and end the webinar today. Thank you so much for joining us and we will hopefully see you in person soon, either at the Hands & Voices leadership conference or perhaps in EHDI 2022.