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NCHAM-Creating Authentic Partnerships: Parents and
Professionals: Webinar Hands & Voices/FL3

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Utah State University.

~~Live Captioner standing by...

>> We're just getting our technologies all lined up here and
ready to go, so you'll probably see some activity on your screen as
we do those things.

>> For those of you who have just joined us, you're in the
right place for today's webinar. I'm moving things around on the
screen, everyone, so allow me to do that, please. You're in the right
place for today's webinar entitled creating authentic partnerships:
Parents and Professionals, which is brought to you by Hands &
Voices and the FL3 initiative.

We'll be starting at the top of the hour. That's in about 13
minutes from now.

So for now you can just get yourself adjusted, have the
volume set if you are listening today. This webinar will be recorded,
captioned, and interpreted with ASL interpreters.

So we're doing our best to try to provide these multiple
modes of communication for everyone today.

If anything disrupts today's webinar, whether it is on your end

or our end technologically or otherwise, know that this webinar is being recorded and will be viewable in the next couple of days on the Hands & Voices website as well as on Infanthearing.org. And keep that in mind also in case there are people who aren't attending live who you think might benefit from today's webinar. You can refer them to this at those websites as well.

Heidi and Lylis, if you would like to add your email addresses under your names over on the left where it says today's presenters, you'll have to take turns doing that. Heidi, you could move your cursor over there and add yours first. And then, Lylis, once she has completed typing, you could do the same if you would like.

>> Heidi: What do I do? What do I click on?

>> Go to your name and put the cursor at the end of your name and hit return and then type.

>> Heidi: Perfect.

>> There you go.

>> Heidi: Okay, I'm done. Thank you.

>> Rivka, you're not moving in your screen right now.

>> She said she muted her camera, which that's totally fine.

>> Rivka: I was off camera until you stop but I'm here. I will definitely pop back on.

>> Okay. Thank you.

Thank you, Heidi and Lylis.

Heidi health department.

>> Once again for those who have joined us, you're in the right place for today's webinar, entitled creating authentic partnerships: Parents and professionals, which is brought to you by the Hands & Voices and the FL3 Project.

Starting in about 8 minutes, at the top of the hour.

>> I apologize for repeating myself, but we have people signing on at a fairly rapid pace right now.

You are in the right place for today's webinar. We will be starting in five minutes.

Remember to click the CC button in order to turn on the captioning feature.

>> For those of you who have just signed on, you're in the right place. We're getting ready to start our webinar that we'll be starting in about three minutes.

If you are wanting the closed captioning button or closed captioning feature, you first click on the CC up in the upper menu and then it will appear beneath the PowerPoint and video slide.

You can stretch the width of that to your liking by moving your cursor to either end and stretching it.

If you need to step away during this presentation, you don't need to let us know. If you do click that, it actually disrupts the flow of the screen for us. So please don't worry about letting us know if you need to step away. Thank you.

We'll be starting in just a moment here.

Lylis and Heidi, are you still connected and ready to go when we reach the top of the hour?

>> Heidi: We're good to go.

>> Lylis: Whenever you are.

>> Okay. Great. Thank you.

We are going to hold on a minute more as people are signing in.

Gunnar, if you could keep an eye out with me for a second interpreter, that would be great. Gunnar, I don't know if I said Gunnar, that's what I meant.

>> Gunnar: I will keep an eye out.

>> Thank you.

Well, I see that we're at the top of the hour so I'm going to initiate recording of this meeting and then we'll get started.

Well, good day, everyone. I would like to welcome you to today's webinar that is entitled Creating Authentic Partnerships: Parents and Professionals, with our presenters, Heidi Klomhaus and Lylis Olsen. My name is Wil Eiserman and I am the associate director of the National Center for Hearing Assessment and Management, which houses the National Technical Resource Center on EHDI at Utah State University and we're delighted to be able to share our Adobe Connect webinar platform with Hands & Voices and the FL3 Project in its presentation of today's webinar. This webinar is going to be recorded - so if anything disrupts your participation in today's webinar, whether practical, whether a logistical nature or a technological one, all of which are possibilities, you'll be able to access this another time on the Hands & Voices website in just a couple of days. Keep that in mind too, if the content of today's webinar seems to be of benefit to somebody you know of who isn't attending live today, that you can share that with.

Today our presenters are going to be speaking at first and then we'll open up the floor to questions towards the end of their presentation so that you can interact with our presenters around

any questions or comments that you would like to dialogue with them about. And you'll do that in a text format.

We want to give a shout out of thanks to our captioner and to our interpreter today. Those are real live people who have talents and availability that benefit all of us, so we're very thankful for their time and talents today and never want to take them for granted. So thank you to both of you who are doing that for us today.

If you need to step away today during the presentation, please don't worry about clicking the option to let us know, as that just temporarily blocks the screen for our presenters and is kind of disruptive. So rather than being helpful, it's really more disruptive. So refrain from doing that if you will.

So without any further delay, let me introduce to you today's presenters, Heidi Klomhaus and Lylis Olsen.

>> Thank you so much, William, appreciate you introducing us and being here today. Heidi is the Executive Director of the Arizona chapter of Hands & Voices. She's also the coordinator of Guide By Your Side. I work with the ear foundation of Arizona and I managed a couple programs. I'm the AZ EHDI program and the ear -- program manager. Today we are going to talk about an area that we are not necessarily the experts in but that we've had some success so we are going to share what we think may have led to some of that success and how that has evolved as we've moved through the last few years. There's a number of different things that we've learned over many years of collaboration. We'll talk about them kind of in the abstract for the first half of this presentation, and we'll include all the topics shown here, and then we will talk about how we applied those things in a project with the pandemic that was both challenging, rewarding, successful, and not always successful. We learned a lot. It was a learning experience.

So the first thing we need to talk about are evolving relationships. I want you guys to be thinking to yourselves: Where am I at in this process with all of the different organizations that makeup EHDI, not just the EHDI coordinator and the parent group but also the other partners that we have and where are we currently at? I can tell you that Arizona has been at almost all of these places at one time or another and at some areas we keep going back to the same place. However, I think we've moved forward across this for a lot of work. I think that we kind of -- I was fortunate to step into a position where parents were already invited to the table, so I never had to think about whether I should have a

parent on a panel or I should have a parent on, for example, our stakeholders meeting. They were there when I got there, so fortunately the person before us had some insight into that. However, we don't always remember to invite a parent where we should. However, the EHDl grant that came out, that HRSA grant that came out, created some forced togetherness, if you want to put it that way, and kind of threw some EHDl coordinates for a loop for a while. And that forced togetherness was a requirement of the grant that 25% of the grant went to parent groups for various activities. Well, that means that 25% of the work in the grant needed to go to parent groups as well. So that didn't necessarily make for a natural pairing, but oftentimes the parent group and the EHDl program needed to get up to speed very, very quickly. For many years, we used to use parents to kind of click a box at the end of a project, and we would show up with a finished project and say look at what we just did for you, aren't you happy, isn't this great, and we would expect them to nod and smile and maybe rubber stamp it. In fact, we weren't terribly thrilled with them when they had some suggestions or they said this wasn't really what we wanted or what we needed. And at the same time, everybody involved thought they were doing a good thing. So we know that we need to have parents at the table and have a seat at the table, but we've also learned that people need to have a seat at the head of the table. And that's an entirely different mindset over the last several years than we've had in the past. Parents in Arizona need to help us set goals and activities. They have joint responsibility for all of the activities, the decision-making, setting the agenda, setting the goals, and how we are going to go about getting to those particular goals. They also do at least half of the work, if not more.

So the only way that we are going to be successful at creating some of those common goals and really the activities, working together, and truly doing an authentic partnership is really kind of building some of that trust and we believe that that trust is built through partially through some mutual understanding. I think that it's important that we share a knowledge base. The field is full of jargon. It's full of complications. State government is complicated and not always logical. AEP's -- what are the goals, what are the limitations, what are the challenges outside specific projects. For example, states sometimes often have very lengthy and difficult procurement requirements that other organizations don't have, particularly smaller organizations that are 501C3 or other agencies.

They may have reporting requirements that aren't very transparent. They may be reporting on other grants that they have. They may be funding their EHDI program through an MCHB, which is a maternal and child health block grant that each state gets. They may be funding it through education funds. They may be funding it through newborn screening fees. Each one of those has its own organizational structure and has its own reporting mechanism and its own way of communicating. So the EHDI coordinator and the EHDI system may have multiple things that are making what seems like a simple task much more complex. I can also tell you that when I worked for the State Department in Arizona, the quickest way to get in trouble was to advocate with a legislator or get into the news. State employees often don't have the opportunity or the ability, and they certainly need to have permission before they do any advocacy or any sort of media relations. And sometimes partners don't always understand that because they're much more free to do that. I can tell you that since I work for a nonprofit, we have that ability to do that and we'll talk a little bit later about some of our strengths. Lives of parents are also complex. One of the things we'll talk about a little later is the fact that parents come with skills and other jobs. They have careers. They have other demands on their time. As you know, many children who are Deaf/ Hard-of-Hearing also have other conditions that are present as well. And children who are what we call Deaf + may have extra medical appointments, there may be surgeries, there may be way more meetings at schools. We also recognize that parents are navigating a system at the same time they're working on changing that same system. That can create barriers, that can create some challenges, but it also can create some opportunities.

One of the things that parents really have to do before they become part of the EHDI system as a participating partner is really be able to make that switch from my own child to our children, or what may relate to the broader population of parents that are involved. We know that every family is unique, but when we're working with building systems, we need to build systems that help most of the families. So being able to step aside from your own experience is very important. Building trust is also -- part of building trust is also that mutual accountability. And I want to make sure that you're realizing that accountability isn't just on the parent side. You don't just, because the state or the Ear Foundation may have a contract with parents, that doesn't mean that it's a one-way street

for accountability. It's important that both of us on both sides of the partnership, do what we say we are going to do. We need -- take responsibility, things that go good and that go bad, and that we continually communicate and Heidi will talk more about communication. But communication kind of underlays all of these sorts of things.

>> Heidi: So now we'll talk about intentional communication, as Lylis mentioned. As she said before, communication is going to be mentioned several times and it is really key to all aspects of what we do together as partners much.

For us in Arizona, with work for us, is having schedules regular meetings together that are very purposeful and very intentional and it involves a shared leadership. So we meet on a weekly basis and it just happens that we do it on a Monday. We found that it works for us and it sets the tone for the rest of the week. And I want to be clear that it's really not a time of reporting, if you will; it's really a time that we check in and make sure that everybody knows what's ahead of us and what activities we have planned, what deadlines might there be. And it's a kind of way to keep each other accountable. And reinforcing what Lylis said a few moments ago about accountability, that goes both ways. We're holding each other accountable and it allows for fewer assumptions and fewer surprises. When we're talking, we talk about what we've already done, what activities have happened, what was successful, what wasn't successful, how do we improve upon that. Then we talk about moving forward. What are the next activities? What do we need to have done? What's our time line? Then we discuss threats and opportunities. As Lylis mentioned we are talking about what do we have going on in our lives when scheduling things? If we have a report coming up, we don't schedule that around a time that one of the leadership members maybe a surgery within the family or they're traveling. Anyone that knows Lylis knows that she travels and is out of the state for the summer, so we know we are not going to schedule meetings or reporting deadlines during that time.

We know that for parents we are not going to schedule things during the back to school thing for August or July for some states. And then talking about opportunities, thinking about funding and thinking about looking ahead and are we going to run out of funding, do we need to increase those opportunities that we have of shared collaboration and shared activities and seeking other

funding and realizing that possibly the parent group can react quicker than government agencies can in ensuring that activities are getting completed.

And then really just taking the time for connecting on a personal level. We are not just colleagues. We have connected on a very personal level. We know things about each other. We stay in touch. We realize that we're equals in everything that we do and that we have things that go in our lives so we take some of those things into account when collaborating and working and discussing things and ensuring that we're just maintaining that communication, opening those lines of engaging with one another allows for a more positive outcome in securing the activities and making sure that they're being completed.

>> So building common goals sounds easy. It sounds like we should have common goals because we're working with the same population, but sometimes it's harder than others and sometimes there are things that get in the way.

>> Lylis, this is William. Could you please try to remember to say that it is you who is speaking when you take turns?

>> Lylis: That's been something that I've never been good at and one of the slides here will talk about other things that I'm not good at but I will try to be better, William. This is Lylis. We are going to talk a little bit about something that you may want to go into in more detail at some point in time and really learn about adult learning and adult learning and learning styles can really either get in the way or can help us create those common goals. Adult learning styles, there's the auditory, the visual, and the kinesthetic and most of you have probably heard of that. But we use those things all the time and are always thinking about what's your preferred mode of communication among the team. I have team members who text, I have team members that pick up the phone and call me, and I have team members that want to take notes or want to have everything in writing in an email. And we need to get to know each other on a personal level so we know what works for us as a group. It's also important that everybody has buy-in to the goals and activities that we've chosen as a group. We know from adult learning that parents are adults, they want to decide for themselves what's important and they want that knowledge to apply immediately, they based knowledge on what they know and what they learned and they can get better at that by learning from other people's experiences as well. And they come with a past

experience and have the ability to contribute beyond the "just a parent." Professionals also have overlying organizational goals that may or may not have anything to do with what they're doing for this project. They have grant requirements for the grants that are related to EHDI and grant requirements for grants that are not related to EHDI. They also have personal experience and educational background. Some of your EHDI coordinators are public health people, some are audiologist, some are parents of children who are Deaf/Hard-of-Hearing. We have adult learning styles and adult caveat that apply to us as professionals. We also have organizational strengths. We think it's really important that you are aware of your own organization. This is interesting because it jumps ahead two every time I click it, William. This is Lylis still. The organizational strengths.

I'm going to try this one more time. It doesn't like to stay on this particular slide.

Oftentimes Department of Health services or Department of Education or those government agencies have a perception of authority and expertise. And there are times when you want to use those strengths where a letter from the Department of Health may be very much more likely to be read than a letter from a parent organization. The opposite is also true, that if you have some populations are very much not going to read a letter from a government agency; they have a fear of government agencies or past negative experience with government agencies or with immigration, so they're much more likely to respond to the parent approach which may be more personalized. There's also strengths in government resources. Oftentimes they already have contracts for meeting rooms and printing. They have multiple departments under the same umbrella that can be accessed such as WIC or the children and [Away from mic] special healthcare needs, other government grants. They have an IT department. They have financial reserves so they have the ability of going longer without being paid than small organizations. They are able to take on bigger contracts without as much concern. But on the other side, smaller organizations are able to make decisions quickly, they can act quickly, they're more flexible to contract with everyone, they don't have to go through that big procurement. It doesn't take a year to get a contract. Then there's a different depth of skills that may be useful on both sides. Your parent groups often have a lawyer, they have an educator, they have an interpreter. They have

a teacher. They have a broad variety of skills amongst those parent groups that really can be tapped into for all of the different things that we could do and they can be really valuable. We also know from our own experience with the Ear Foundation, about half ever our staff are parents who are Deaf/Hard-of-Hearing and there is no one more motivated and more committed to what we do for the families than a parent of a child who is Deaf/Hard-of-Hearing.

>> Heidi: So now talking about self-awareness, when we talk about self-awareness we are not talking just about individuals but also organizationally. We have to look at it as a time of therapy. For most of us we know we all need therapy at some point or another and it's really taking that time to understand ourselves individually and organizationally what motivates us, what are our triggers, and why. How do we communicate? Like Lylis was talking about earlier, do we prefer email, do we prefer text, phone calls? Not only that, but how do we learn? Going back to the adult learning styles, taking some of those things into account and really being aware of those things not only for yourself but as an organization as a whole. And then just really realizing that there's always room for improvement, no matter how long we have been at it. I have been involved in this system for about three years now and Lylis is 20 plus years and regardless of how long, what our background is, what our education is, what our experience is, there's always room for improvement. We're in such a fluid situation, systems change, availability of technology and things are advancing. We have to stay -- up and adapt and that ability to grow and reflect and to really realize, okay, what's going well, what's not going well, how do we react? Was that appropriate? Did that maintain -- was that consistent within our mission and our goals? Are we maintaining professional behavior? And then of course just really accepting responsibility, whether it was successful or not. Just owning those pieces and realizing that moving forward, you want to evolve and get that much better.

And then of course with the whole last year and a half with this pandemic, I think we've all learned to have a little grace and forgiveness and just really having that ability to forgive not only ourselves but organizationally what we've done together and just accepting those things and moving on.

>> Lylis: It's also important to recognize when there are opportunities because those opportunities change as the climate changes, as the environment changes, as political parties change,

as other federal projects come into play, as pandemics happen. So it's important that we maximize our efforts. Being at this for a very long time, there's always more to do than we can get done in the time that we have. However, we can make sure that we're making the most of the time by using those opportunities as they come up and really leveraging them.

Timing. Oftentimes there's money at the end of the grant or less money at the end of the grant. Most of the time it's a use it or lose it situation. One of the best things I learned in undergraduate work was always to have a list of things I would do if I had the money and the time to do them. Always thinking ahead, I always had a five-year plan and always had those ideas of if an opportunity comes up that I can do this I can make use of that opportunity immediately. One of the things that's important is to use the interest and motivation for change that's there. If you have somebody come to you, for example recently we had a hospital that's been in trouble come to us and ask for help, well, we probably are going to switch gears and not do the hospital that we originally planned on working on; we are going to switch to the one who really wants to change. So being flexible, which is not one of my strong suits, but being flexible and going with people that are ready to change or that are interested in change is really important. Using the available resources. If you have someone on the team that's an epidemiologist, we probably want to do some data things. If you have someone on your team that's an IT expert, I'm very jealous and I would like to have him move to Arizona. And if you have someone who is in media or is a lobbyist or something like that, you can use those people and take advantage of their skills and the opportunities that you have.

You also need to stay true to your mission. Anybody who's been on a committee with me has heard me talk about scope creep. When you start expanding beyond your original plan and your original mission and you end up with something that wasn't what you originally intended to do, and sometimes it really dilutes your effort. I write quite a few foundational grants too as well as some of the government grants and I really believe that you can't force the fit. You need to stay true to your mission. Being really aware of what your mission is and what your capabilities are and recognizing that this is an opportunity that fits. It's better to have an opportunity that fits. It's better and you'll be more successful than if you try to force the fit.

I also want to talk a little bit about sustainability beyond relationships.

We know that relationships are really important. However, I want the things that we do, the quality improvement that we do, to last long beyond when I'm here. I want that to last until as long as possible. So when we're working together, we're trying different things, we're doing quality improvement, we're doing the plan/do/study/act sort of paradigm, but we also want to be moving towards system change. We want to change policy. We want to change what agencies do, what organizations do. Ultimately we may want to change statutory and legislation and the rules that -- statute is what tells us what we can do and the rules are what tell us how we can do it. Those are not easily changed, but if we found something that worked, that's what we want to do. We want to get those things into more sustainable and institutionalized. We want on going renewable funding. Something that works that we know that works that we know is going to around for a long time, we want to make sure that that is funded by something other than grants if we can. We think it's important that we support, have public support and public perception of not only our own programs but each other's programs so that that will continue beyond just my relationship with Hands & Voices or even my relationship with Heidi, but that it will be -- that I'm supportive of her having a seat at many different tables and taking a leadership role with those many different people.

So this leads us to our practical application. We are going to talk a little bit about our pandemic response. And once again, I'm having every time I click on it, I go ahead two. I don't know if there's something you can do about that, William, or just live with it. Anyway, the pandemic response, as you all know, within a couple of weeks we went from going to the EHDI conference without a mask to coming home and everything was shut down within a week or two. Even though we probably should have seen it coming, there are lots of things that we really didn't see coming. One of the things that came up very quickly before the end of March was that the pandemic required services to be provided to families in unconventional ways that we weren't used to doing. We got together and started looking at what kind of opportunity does this present, what is it that we have as available resources, what funding do we have available, what do we already have in place, and what is it that we need and who's the best person to do that?

Which organization and agency has the strengths to do what we need to have done?

So we had a pre-pandemic partnership. So we had an existing relationship dating back all the way to 2015. So there had been a collaboration on an actual teleintervention project between the School for the Deaf and Blind which is Part C provider under IDEA for children who are Blind, Deaf and hard of hearing, we had built trust and established relationships. We were already in communication on a regular basis and were picking up the phone and talking to each other. We had co-written grants together, so we already had that going on for us and that was a big deal.

The initial response was also -- our initial response was to have the Ear Foundation of Arizona, because they could do it in a very short amount of time, over less than a week we purchased 109 tablets, we had 70 sim cards with month-to-month prepaid plans and we used our existing staff and parents and the early learning program staff to actually distribute equipment. We accelerated training. We were able to -- because we'd already established some training within the School for the Deaf and Blind, they were able to take staff trained in other states, and thanks to other states who had been doing teleintervention for a while because we had some of your people already trained in Arizona, we had staff trained in that pilot. They were able to create captioned, ASL professional training videos and able to startup right away. Teleintervention included Deaf mentors as well. And everybody had to learn how to use Zoom and how to make the most out of a virtual session.

>> Heidi: To continue talking about the initial response and to elaborate on the organizational strengths as Lylis was mentioning, in regards to parent support, we, as parents within the Guide By Your Side program at Hands & Voices we were able to step in and be a part of some of that distribution of equipment across the state and educating parents on the use of the tablets that were being used and then taking the time to practice with parents on Zoom. Some of these families really didn't even use any type of equipment before, any type of tablets or devices, and had no idea how to connect virtually. So we were taking the time to really walk them through those steps. Some of them might not have known how to connect to Zoom so we were explaining those things and how to make sure how to connect with the early learning program providers. And then also just giving the opportunities for

families to be supportive through Zoom events from our own organization. What this allowed was us as Hands & Voices, it freed up the teachers from the early learning program -- we had parents that were familiar with those tablets, that were familiar with the utilization of Zoom, so that's something we had been doing as well. We were able to take on that role in educating the families on that use and allowing the early learning program focus on what they needed to do in shifting gears to providing family visits virtually via Zoom.

>> Lylis: We've titled this slide various things over the last few months. And basically, when we had a time to kind of take a breath, we had to do some self-awareness and some reflection. and what worked and what didn't work. And there are many things that didn't work or didn't work as well as we would have liked them to. We found that the prepaid sim cards were adding time to my time I didn't have. We found out they didn't work in many areas, including all of Tucson, which is the second biggest city in Arizona. That was a big deal. The SIM cards came with one internet provider. And in fact the internet provider that was labeled on the cards that I thought I purchased was actually not the internet provider that was being used by that system. So we learned a lot of different things. We also learned that I'm not good at tech. I used to be but I'm not anymore. Obviously not. I don't understand the difference between 3G, 4G, 5G, whatever it may be. We also learned that we really, really really had to communicate and some of the things that we did for tracking and inventory management weren't working at all. In fact, there's a certain number of tablets right now that I have no idea where they are. We're giving tablets to two and three-year olds. A lot of them will be broken, they will sit on them, jump on them, drop them, things will happen to them. We have families that are very transient so oftentimes we wouldn't know where they were and where the technology was or we would have to catch up with it. I didn't have the information technology support that I needed. I had to find parents and other people, including a 26 year old nephew of mine that came in and had to help me. They had to rescue me with the technology because I really didn't know. We needed a larger screen for the Deaf mentor program. Learning ASL on a 7 or 10-inch screen just wasn't adequate. So we really had to learn a few things and really be reflective. One of the things was communication. Communication was very much one of those things that we set up systems and

they didn't work. And part of that was very much my fault because those early interventionists who had known me for a long time knew that I'm very responsive to an email to my main email, and also very responsive to phone calls and text messages, whereas I wasn't as responsive to the EHDI email and I wasn't as responsive to a shared spreadsheet online. So we really had to figure out how to do some of those things.

>> Heidi: Some other things that we had to figure out was in the process of distribution is some of those families that we're trying to reach within the sovereign nations. They had curfews in place, there was nobody in or out with very limited supplies and access to communication. That includes rural areas, very remote locations. And then there were those families that had language barriers. In trying to get this equipment out to those families, there were times when something was wrong on the addresses and there isn't an exact address and there are certain ways of labeling it when you're shipping it and then having those language barriers in place made a difficult connection with the families to ensure we're getting the correct information.

And then as Lylis mentioned, talking about the populations and crisis and meeting families where they are. Transient populations, families that were losing their jobs, they were couch surfing and family and friends, they had children with other needs and things happening in their lives. Some families were staying in hotel rooms and temporary places. It wasn't necessarily an ideal situation for us to ship something because they may not be there next week. So really meeting them where they are. Lylis on one occasion had gone out to somebody at a hotel room and met with them, of course with protocols in place and was able to get a tablet in hand and talk to the family and they were able to take it with them as they moved from place to place until more permanent conditions were in place. Just really taking the time to find out how to meet the families where they are. And being fluid and flexible and adapting to the situation, which as Lylis said, it's not her strong suit and some of us have some issues with that. The pandemic has really taught us all that we have to be a little bit more flexible when we're trying to ensure that we're getting the families what they need.

>> Lylis: And we had the opportunity to rework this, that we don't always have. Sometimes we have one shot at it but this time we actually had an opportunity to try again. And there's AMCHP

CARES Act funding that became available that allowed us to buy additional equipment and rework some of the things we'd done. It also gave us the opportunity to communicate with the actual providers. Some of them took a little bit of work to get them to really tell us what wasn't working, because they're such nice people, the early learning program people, you've never met a nicer and more polite group of people, and they're so appreciative of the opportunities that we'd given them that they didn't want to complain. But we really needed them to tell us what wasn't working and they were able to do that. I haven't figured out how to get internet to certain parts of the state of Arizona but things are getting better. And we were able to get new equipment with larger screens. We were able to get data solutions that worked better. One of the things we were able to do is really communicate and talk about long-term what is this going to look like. We're past that initial couple of weeks when we got 100 and some pieces of equipment out into the field in two weeks. Now we need to look at what's going to happen later. What's going to happen when the pandemic is over? Is it going to be over? How long will we be doing remote services? We know some distance learning is going to stay. It works really well for families who have children with special medical needs. They don't want somebody coming in the house. We also know because of what we learned about sustainability beyond the relationship and beyond those grants, is that we need to align with each other's goals. So some of our solutions were chosen because they fit with the School for the Deaf and Blind, what they had been doing at the elementary and high school level, including how they got hotspots and how they tracked things. So it made sense to do something that aligned better with long-term solutions in order to put things into place. The long-term plan was to make sure that we got equipment to everybody as long as they needed and then to repurpose the equipment for however we could do that.

>> Heidi: So continuing to talk about opportunities and solutions, in regards to the CARES Act funding, it really allowed going back to what we were speaking to earlier, that building of relationships and involving increased partnerships. We were able to enhance that parent support. We knew that reaching out to a parent only once in a while wasn't going to work. We needed to continue to maintain contact and continue to give them the opportunity for virtual support. And in doing so, we're continuing to maintain those communications with the early learning program

providers. And what stemmed out of that is that ability to join some of the family visits. So we're now joining visits with the early learning program and providing a joint support system for the families. It's building upon that mutual trust and understanding of one another and what we can do organizationally.

And just with this being a maternal child health grant, it's taking that family centered approach. It really allowed us to have this equipment that was being provided for these families, to use the equipment for all the things that they needed, that included telehealth, any teleintervention, home visiting services, and of course parent support.

When it came to engaging a diverse population virtually, we had over time discovered many opportunities that we were able to provide support in what we were doing. One of the first things we did as Hands & Voices and Guide By Your Side program is create an event called what's up Wednesday. It happened to fall on a Wednesday and that's what we ended up dubbing it and we have been doing that since the pandemic started and we continue to do that today. And the topic focus, we listen to what the parents' needs and frustrations and concerns were. Sometimes we would have an audiologist come on and talk about technology. We invited an SLP come on and discuss how to develop language and provide tips for parents to use at home with their children. We've had some events, we did a virtual family camp which was an amazing turn out of 28 families that stayed for an entire five and a half hour day. There were four sessions that included a mental health piece, a family literacy hour, and then also a Deaf/Hard-of-Hearing young adult panel. We were also able to invite a Deaf actor from the Manned Lorian series, Tori -- to come and have a fun hour with the kids. And in doing that we also presented the opportunity, it was all interpreted in Spanish and we had breakout sessions where the literacy hour was provided in Spanish directly from a native Spanish speaker that's a previous teacher of the Deaf. And so we had Spanish speaking families that joined us for that. We had families from the sovereign nations that were able to connect with that eventually. And the feedback we've gotten from the camp, everyone loves the literacy hour. We then born the monthly event that we call story BEATZ. Every month there's a new book that's introduced and led by a parent guide that is a former teacher of the Deaf and has more than 20 years of experience in serving families and she's a parent of a Deaf child herself. She provides literacy

and language tips and does a music time, story time, bubble time, a fantastic hour. And we're reaching families all over the state. And it's an opportunity that families that we normally wouldn't have hit even pre-pandemic because we don't have people -- we don't have the ability to host events in all areas of the state. And this gives an equal opportunity for all families by engaging populations virtually.

We're supporting the sovereign nations and supporting their families depending on location, and not only that, we're supporting families with varied cultural backgrounds and languages. We have Arabic speaking members within Hands & Voices, we have bilingual Spanish speaking parent guides, we have guides that are fluent in ASL. We have a variety of capabilities and skill sets that are utilized not only by us as a Guide By Your Side team but also the early learning program. Our Arabic speaking person has joined family visits with the early learning program because it's made an impact on the ability to connect with those families and building that trust between the family and the early learning program.

It's really built upon all the relationships and all the collaborations within how we're supporting families. On the bottom of this PowerPoint that will be available too, there is a link here if you would like to check it out. You will see the StoryBEATZ hour and you will see permission from the families to record that. It's a fun hour and it's neat to see all the children dancing and being engaged and having a good time and getting the support that they need. It's not only what they need developmentally but also socially.

So lastly we'll talk about sustaining what works. So obviously the ongoing HRSA EHDI grant is going to continue support parent guides, Deaf mentor and Deaf/Hard-of-Hearing guides. Because it's been so successful and the activities that we're doing and reaching families and engaging parents, we are going to continue to fund the virtual events. But then that also means we have to continue looking for funding because we are going to outgrow the funding we have. We are going to continue to look for grants and looking for opportunities to co-write the grants together and providing activities and services for the families.

And also here in Arizona there's been some legislation that has come up in the continued support of Medicaid coverage for virtual teleservices that the Ear Foundation continues to support. As Lylis was talking about when mentioning about equipment and the hotspots and searching for data plans and things like that, she

aligned it with the ASCD and what they were already using because the long-term goal was to donate all the equipment to the early learning program so they could continue to sustain it beyond what we do. As the families are aging out and tablets come back in and new families come, they are able to get the new equipment out and maintain the IT side of things for that. And of course, we are going to continue as parent guides within the Guide By Your Side program, we will continue to support the early limit learning program. We still get asked to join the family visits and we continue to build those relationships and build that trust and understanding among each other. And we have ongoing discussions right now about increased support of early intervention, enrollment, and will continue to work on that as well.

So now we're at the end and we want to give the opportunity for everyone to put questions or comments in the Q&A box and we're sure Wil will get those. Thank you for the opportunity.

>> Wil: Thank you, everybody, this is Wil Eiserman from NCHAM. I'm going to move a few things around on the screen here. While I do that, be thinking about what your questions might be for today's presenters. So you'll see a Q&A box over on the left here, into which you can type a question or a comment for our presenters to respond to.

So if you have something you would like to put in there, one of the most common questions is: Are there slides or any handouts from today's webinar that you all are planning to share with today's participants?

>> Heidi: I do believe that that will be available on the FL3 website along with the recording of this session.

If not, you can reach out to either Lylis or myself at the emails that you see on the screen.

>> Wil: And I'll post them again in larger view here as well.

Sorry. There we go. The next question is could you repeat the website again that the webinar will be posted on?

>> Heidi: Hands & Voices will be posting that on their FL3 website once it's available.

>> Wil: Okay. Great. You're getting some commitments.

How important is a base level of funding for your parent leaders to sustain your collaborative partnerships and activities with your EHDI program?

>> Lylis: If you're okay with me taking that first, Heidi, you can chime in after. We pay our parents for everything they do. And I

think that the mindset that has changed over the years is that we also expect professional level of work from our parents. So I think that it's not just a matter of base funding for the parent leaders, but it's what we're asking those parent leaders to do. And we're asking them to do real work that should be compensated at a level that's commensurate with their experience and background and what they do. So I think that's important. I think it's difficult, as anybody who's worked for a nonprofit and I have been with a nonprofit for 21 years, is that you're always looking for sustainable funding. And sustainable funding is a challenge forever. So some things you just know you will always be fundraising for. But we have to have patterns available long-term. We have to have parents that are compensated. So I think that the grant has allowed us to have a base level of funding for a set number of years that will allow us to build from there, but I'm always worried about sustainability.

>> Wil: And the next comment is I love that you pointed out that parents are learning to navigate a system and change a system at the same time.

How do you assist and/or support parents in learning to navigate the system? Do you have any favorite resources you use?

It can be very overwhelming.

>> Lylis: Basically how we teach people to navigate the system is we refer them over to Hands & Voices so that Heidi can help them navigate the system.

And I think the rest of it, the rest of the answer, how I teach Heidi how to navigate the system or kind of the behind the scenes things, that's the communication, and that's the communication and the relationship building that makes it comfortable for us to ask each other questions about how does this really work at that agency, what can I really expect from that agency, how do I navigate that agency or that organization. So I think it always goes back to communication.

>> Heidi: If I may elaborate a little bit, I would like to say also that it depends what steps or where they are within the system of a family that we're servicing. So maybe it's a family that's trying to understand what the transition process looks like or maybe a family that doesn't agree with something once they reach the preschool level and they're wanting to go back and ask questions of what should have happened at the transition. As Lylis mentioned, it's who do we need to ask, who do we need to contact and how do

we get that information, so it's going back to the resources. I don't think there's any one set of resource, as far as one go to that I would recommend because it really is fluid. It really depends on what it is that the family needs. Are they navigating an audiology appointment, are they navigating E NT, is it transition, is it Deaf mentorship. I will say that the Hands & Voices website has great resources there that we continue to use and use on a regular basis and it's really about diving into each family's case and finding the particulars of what they need.

>> Wil: We have time for maybe one or two more questions. Here's the next. Our state is divided between different silos. It is hard to establish relationships even without COVID restrictions. How did you start the conversation? Regretfully, there are deep divisions and misunderstandings that need to be addressed first. What do you recommend as the first step?

>> Lylis: And I can tell you that there's no easy answer for that, as you already know. If there was one, you would have found it already. But I think it comes back to the communication. One of the things that we started, because of the pandemic, that we will continue, is we don't do as many conference calls, and that's true across the board. I do way more Zoom calls, and that opportunity to see each other's face and get to know each other better, Zoom calls allow us to introduce our dogs, cats and children to each other. And I think building some of those personal relationships and the time together and the time communicating, so it always goes back to communication. Can you add any magic to that, Heidi?

>> Heidi: I think you said it beautifully. I think it's honestly as we have been saying throughout the entire presentation, it's good communication and not giving up. If you don't get answers the first time or the second time or the third time, just keep reaching out, keep communicating, keep trying to establish those relationships. It goes a long way.

>> Lylis: To go back to something Heidi said earlier, forgiveness, moving on and having a little bit of grace with each other. I am, to a fault, blunt, and that works against me quite often with Heidi and with others as well. Heidi has learned how to navigate my way of communicating and she's also figured out how to tell me I'm being too blunt and I need to dial it back a little bit. So I think getting to know each other and learning more about each other can really help demystify and take care of some of those misconceptions.

>> Wil:

>> Heidi: I just want to add one more thing on to what Lylis just said. You really need to be open to that also. You have to be receptive and willing. You can't go into anything with a mindset that is one way and it's your way or the way that you've always done it is being open to those changes and open to adaptability and open to accepting everybody as they are. Thank you.

>> Wil: I'm going to be blunt, and Lylis, we love your bluntness, but we're at the top of the hour so we are going to wrap it up here. We need to let our amazing interpreter go on to her next responsibility. She interpreted non-stop for a full hour in the absence of a partner. So thank you so much for your services as well as to our captioner and of course to our presenters and our behind the scenes support folks as well as to all of you who attended today. Before you run off, click the "click here" button in the middle of your screen to give us feedback on today's webinar. And you'll also get a certificate of attendance today. Once again, today's webinar has been recorded and it will be posted along with some handouts or the slides on Hands & Voices.org in the next couple of days. Keep that in mind and thanks, everybody, for all of the work you do to support children and their families.