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>> Hello, we're talking right now, can you hear us?

>> Can we perhaps have the system call her cell phone directly and have her... chime in that way?

>> Brenda, thank you for joining, Barbara is here -- we're going to wait for Barbara to get back and talk really quickly about logistics.

>> Okay.

>> So... everyone has access to the slides right now, in the lower left-hand corner, that's how you can forward your slides. If you feel uncomfortable and don't want to forward your own slides, one of us will forward them for you.

>> Luis: Hello and welcome to the sixth installment of our series. My name is Luis Valdez. We'd like to thank all of you for joining us today. Before we begin, I'd like to address a few logistical details. Before the program presentation, we'll provide a brief introduction of our speakers. Following the culmination of all presentations, there'll be a time for questions, because of the number of participants, your telephone lines will be muted throughout the call. However... we'll unmute your phones one at a time during the question-and-answer time at the end. You'll need to press pound and star sound on your phone to be unmuted to ask your questions. If you're using a microphone on your computer, you can raise your hand by clicking the little icon at the very top of the screen that looks like a person raising their hand. You can also submit questions at any point during the presentation, via the chat box on the webinar console. You may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please note, we may not address every question and may combine some questions. This webinar is being reported and will be available on AUCD's webinar library. There'll be a five-question evaluation survey at the close of the webinar. We invite you to post your feedback on the topics.

We will start off with a very quick overview of how the DDF mandates this core function, followed by OI/DD's definition of demonstration services. We will then have presenters from two different UCEDDs expanding upon how their program addresses this core function through their program activities. We'll conclude with a period for questions and answers.

Previously we held our first five installments on interdisciplinary preservice preparation, continuing education, community training, technical assistance and model services. The webinars are available in our library and a tip sheet will be developed for each. This particular installment will focus on demonstration services. Here's a list of all of our upcoming webinars planned in this series.

Section 153 of the Development Disabilities Assistance and Bill of Rights Act outlines a series of core functions. The act includes a specific text, provision of community service that may provide services, supports and assistance to the person described in clause I, through demonstration and model services. That text was subsequently split into two UCEDD core functions, model services and demonstration services.

Further... OI/DD issued a final rule in 2015, providing guidance on implementing the DD act. In this guidance, OIDD mentioned the name for each UCEDD to have a written plan for how their program will implement the core functions. This will also be a topic of a future installment in this series.

This is echoed in the UCEDD funding opportunity in which each applicant must provide a five-year plan for carrying out the core functions as outlined in the DD Act.

Finally... based on OIDD's logic model in which they provide clarifying definitions for each core function, the definition they provide for demonstration services is as follows: Services that field test promising or exemplary practices and may be integrated with training, research and/or dissemination functions.

First, we have Fran Goldfarb and Barbara Wheeler. Fran is a staunch supporter of Peer Advocates and family nav -- navigators. Barbara Wheeler had a 30-year history with the UCEDD, writing and administering grants and contracts that began with addressing barriers to full community inclusion for individuals with intellectual and developmental disabilities. Please join me in welcoming Fran Goldfarb and Barbara Wheeler.

>> Fran: Good afternoon, I'm going to be presenting first and then Barbara will be taking over after that. I'm pleased to be able to talk about our demonstration project, the parent partner training academy, which was really focused on developing a parent partner certification program in Los Angeles County.

So... a little bit of information about mental health parent partners. Like other family support professions, mental health parent partners are parent professionals. They're paraprofessionals and they're really drawing on their lived experience. There is no university course of study for being a parent partner and frequently, we see that parent partners learn by doing, rather than learn to do, which means that much of their training is on the job and situational.

They participate as part of mental health services team and they also help represent the voice of families. Currently, there is no state-level certification for parent partners in California. Other -- unlike other states, such as Iowa and Texas, which do have state-level certification.

So... in 2016, Los Angeles County Department of Mental Health, which is the largest mental health program in the country decided to launch the parent partner training academy and this was really to establish local professional standards of support for parent partners by developing a certification within the Los Angeles County Department of Mental Health.

The program was really parent partner-driven and parent partner-informed. There was a strong desire on the part of parent partners to have a training and certification, as well as... they really identified the topics that were relevant to all parent partners and also included specialty topics for parent partners working with select populations.

The project was funded through state-level Workforce Education and Training funding. Which put a rigid timeline on our project because any unspent funding by the end of the project year had to be returned to the state. During the course of this project, it was decided that this training and certification was going to be mandatory for all wrap around parent partners who were starting a position.

So... the parent partner training covers four programs. Specialty skills, which is really like a three-day continuing education symposium, general skills, which was parent partner training or essential skills training we developed. Supervision and program integration, revision training for people who supervise parent partners and then... a program evaluation. And review.

The original thought for putting this program together, to develop and conduct three levels of training for parent partners. Each of the trainings were going to be about five days in length. They were all to be skills-based and the hope was that it could be tied to the requirements for national certification through the federation of families for children's mental health.

We identified three levels of training, including foundation skills, which were for very new parent partners, who'd been working for two years or fewer. The third level was for parent partners involved in doing training and supervision of other parent partners.

As with so many best plans, we discovered that some revisions to our original plan had to be instituted. This was based on feedback from the evaluations from Department of Mental Health staff, our master trainers, the co-trainers for the pilot, as well as our evaluators and one of the things that we really discovered was there was no clear definition of who needed foundation skills and who needed the direct service.

So... the decision was really made, rather than have three distinct trainings to combine them into one training that we call the essential skills training.

This train is now a 12-day training. Covering 72 hours. It supports preparation for the Los Angeles County Department of Mental Health, Parent Partner Certification exam. It's required of all parent partners entering into a wrap around program. The training is very much skills-based. It's looking at what are the essential skills that any parent partner or parent advocate needs, regardless of the agency that they're working for or the type of program. We liken it to... you know... when a psychologist is, is working on their degree -- they learn how to become a psychologist. They learn the foundational skills and... then... they make specialized, in early childhood or in prison populations, but... they learn those foundational skills and that was the basis for this training.

The topics may be addressed several times throughout the training. We go into items for greater depth. We also want to incorporate other learning and also to increase opportunities for practice. We also developed a two-day training of train the trainers to look at sustainability by making sure there were enough trainers to be able to keep up with the need of parent partners. Anyone becoming a train the trainer not only went through the two-day training, but they also had three observations and feedback sessions during their first course.

This just gives you a little idea of the content of the training, when we originally put this together -- we were handed what is called the list, everything that parent partners and parent advocates felt was important in training parent partners. It covers 21 essential skills areas and 20 different topics. We got it to a somewhat more manageable form. Just to give you an idea, this is the content for the training of trainers two-day training, really helping folks learn how to, learn the curriculum and work on their training skills.

So... the Parent Partner Training Academy. To date, we've held 19 essential skills trainings. That we've had well over 200 people. This number's a little bit old. Who have taken the training. We've had over 84 and again... this number is quite a bit higher at this time. Completing the 12-day training and... those who have taken and passed the certification test. We also have conducted a master trainer training as well as three training of trainers.

There've been a number of challenges. Firstly, conveying the purpose of the training. We also learned that the idea of having trainings specifically for parent partners was incredibly important to the parent partners and the agency. We had to look at different levels of training versus training for everyone. As I mentioned, we had an unyielding timeline that we had to adhere to.

Also... our parent partners were expected to keep up their productivity during the training. We looked at issues of keeping discussions on point and understanding that many parent partners had no experience with Higher Education and... for many, this was a very different type of learning.

So... our next steps are, really... expanding and updating the training. Developing more continuing education opportunities. Looking at developing alternative versions of the certification exams and... then, also, supervision and program integration, expanding the program into other counties as well as other programs to utilize a parent paraprofessional.

I want to talk very quickly about the evaluation. And... phase one, which was our, our three-separate trainings. Initially we didn't see a lot of change in people going through the training. Some was because parent partners self-rated themselves high, initially. We did see changes from pre to post-testing and saw regardless of whether people received their training from, from me and my co-trainers or from people that we train to do the trainings, that the outcomes were very similar. That training services was also very high in those phases.

What did people like? They like the motivational interviewing, resources, ways to tell the story. The goal of the parent partner. Learning about brain development and trauma, as well as systems. They love the process of role play and sharing stories and resources. We were very gratified that areas they asked us to improve on were things like parking and coffee, as opposed to content or relevancy of the training.

And... I'm just going to speed through these, so I can be fair to our other presenters. In developing the tasks, we found out that, again, having a parent, have parents input and actually, parent partners participated in writing the exam was extremely, extremely valuable.

And... now, we're looking at how we are going to maintain certification and continue with the need for additional training.

Here is our team. At this point, I'm going to turn it over to Barbara.

>> Sorry... I was just getting water. Okay... my, my project, that I'm going to describe is a bit different. But... I, I do feel that there's much to be learned from this type of project in terms of the demonstration concept that is trying to be emphasized.

Five years ago, we started working with the Vietnamese population, primarily because -- let me see, primarily because they are of the Asian subgroups. That's Chinese, Japanese, Korean, et cetera. The Vietnamese population has the highest percentage of persons to get services from California's regional center system and... for the most part... the, the amount of money they get is less than compared to other groups.

All of the Asian groups get less than white families. California has terrific data that the Department of Developmental Services collects, so... we have good data on whether these kinds of things are actually, whether there are disparities based on race, ethnicity and language.

I put in the two bullets because... we also field tested this at two different regional centers. And so... that was also of interest. We have found, working with the Vietnamese community that there are three major barriers. Parents, generally have low expectations of their child. And... they would never describe it as that. But... most of them, regardless of the level of ability, of ability, they, they want their children to be happy.

So... they're, they're really satisfied with -- they're playing computer games, et cetera. One of the things we really tried to work on in this project, to raise their expectations of what their children can do over time. The second one... that we found... was, their participation in the ITT process is not compared to white families. They all attend the ITT meetings, which is kind of like the IDP for special ed, but they don't speak up and they very rarely will challenge what the regional center is going to say to them.

The other areas that we picked up on and some of that we learned from Tamara Heller's work, we were interest did in what the expectations of aging caregivers are. The vast majority of people lived with their families their entire life. They don't live in community care facilities or... other kinds of services outside of the home.

So... we were interested in trying to get information caregivers and to get a sense of how they viewed their children, what kinds of services they were getting to get a sense of -- do they know about the gamut of services, et cetera. And who would be taking over the caregiver responses that they currently are doing. In terms of expanding the expectations of Vietnamese parents, we asked people what they wanted, but... for the most part, this doesn't sound very nice. We imposed topics that we felt our parents needed more information on. And... as it turns out, they actually enjoyed learning about all of this. So... the first one was supported living. One of the explanations that families would give us about why their kids stayed at home is... they really worried that if they were left -- they were getting services in the community, that their children would not get good services. There'd be nobody to monitor these things.

Employment is a big one. We gave information on sheltered workshops which the majority are in, to not at all, all the way to community interrogated employment.

A number of them love education. But not enough of them know their children can attend community colleges, in particular, in California and get prepared for what we call college to career programs, which is a great program we have in California.

The other is that we imposed this one. We were interested in their conception of their child's sexual development and... how families felt about their children having adult relationships in the long run. Let's see here... whoops... sorry. I'm not doing too well with this.

The other area in terms of IPP coaching, we created this model that was basically looked at, walking families through the whole process of the IPP. We found they attend the meetings, but they don't participate. So... we essentially tried to, then... work with families on moving them through the IPP process, so... by the time they got into the purple zone, right in the middle, they were ready to participate in the IPP process.

We also followed them afterwards to see if they, if they spoke up and... mentioned what they wanted to. Which we had planned for, and did they get it into the IPP? Many times, what we heard from them was, they asked, but the regional centers, if they countered them, they didn't engage in any type of dialogue.

So... one of the cultural issues that we really worked on was... that in our system, it, parents have a right to challenge the system view of their child. They have a strong role and so... that's been a hard one for people to learn, but... I do believe we're starting to make more progress in that area.

The third area, I think I mentioned earlier, was that we borrowed from the work, the futures planning activities that Tamara Heller had done. We focused more on caregiver needs and... we did, we did do a survey and found that, as I mentioned, parents planned to take care of children their whole lives, at home. And... when they asked them the question, what happens when you get sick or you are no longer able to care for your child? For the most part, people didn't have good answers to that.

So... the question of who will care for my children, we asked about siblings and... other caregivers and... -- something's happening.

A number of them said their siblings would end up taking care of their children. When we asked them, had they talked to their children about it, they said no.

What we have found in other groups is that many siblings want to help when they're no longer able to do it, but... the difficulty is that many of them get married, they move out of the state, in order for job opportunities. It means that, even if they're willing to take care of their siblings, they have to move them outside of state.

So... it became very clear, if we did our survey with families, that, that essentially, they weren't quite ready to plan for things. And when we asked them, what about paid caregivers? As I mentioned before, they were uncomfortable with this because they were worried this wasn't going to be a good option for their kids. They didn't trust the system. In terms of where kids with I/DD live in our state, we gave them information about condos, living in their own homes, et cetera. This was an interest to our families. Most of them weren't sure that their children could do this. A number of them had already thought through, they had a place where they could live, but they hadn't thought through who would provide the caregiver support for them.

That's something that we've been trying to work on. A number of years ago, a program called Pacific Bridge was started. It was a home purchased by a non-profit and they observed six adults with I/DD and... they made sure that the service providers were also Asian. It was Asians serving Asians in one home. When we presented this to our family, our families were thrilled about this. Five bedrooms, three and a half baths. Six Asian, adult male tenants. Considered level two community care facility. That was helpful because it had standards associated with it. They wanted to know, the parents, how can we start our own care level two community facility. We hook them up with the areas, the Orange County office. Of state council who is now working with them. They really wanted them to make sure that it qualified as a level two CCF. Which is a good model for the rest of the state, et cetera. They're still in the process of doing that. In terms of services that will be available, when we presented the whole issue -- it was a great eye opener for families. Again... the question they asked was, how many independent living services provided and supported living providers could speak the language, to cook the food their kids would like, et cetera. This has become a systems issue that works -- we're working with, with our state council on how did we try to recruit more Asian providers who can provide supported living and independent living services. That's not as easy as it sounds, I won't go into that at this point.

I wanted to end up talking about what is capacity building. It's so easy to provide training to groups that are underserved, but... the reality is, is we wanted it to be sustainable. So... what we did was, when we worked with VPDCA, we started it, we picked the people to do the training, but... then, we have them identify within their organizational structure, program coordinators. I'm going to,

I'm going to just -- I'm going to talk in a moment about organizational structures, financial stability, program quality, planned growth and long-term sustainability.

So... oh... did I run out of -- I must have run out of -- am I doing --
>> Go ahead.

>> What?

>> This must be my last slide, I guess. I actually had more slides. Anyhow... so... in terms of their organizational structure, I had nice pictures, but I think they're not part of this. In terms of their organizational structure, they had a Vice President and a president and nobody else. They were doing everything. Within our grant, we told them, they needed to identify program coordinators. We had them identify program coordinators that would coordinate training going forward. A program coordinator that would, basically, coordinate the IPP coaching model that we practices and Fran was a key, sort of, consultant to that process, as well as the Orange County office of the State Council who worked with them about the IPP process. They identified a program coordinator, basically, who would deal with aging caregivers.

We have found that that's a very good model. We did the first round and now we have three people that have to sustain it going forward. In terms of financial stability, we helped the VPDCA after our grant was no longer funded to submit a grant to DDS, as part of a reapplication process and they just got funded to continue the project for one year. They asked for two years. DDS only gave them one year.

So... that they can, basically, continue what we started, using their own infrastructure. We also worked with them on keeping, increasing a database that, where they can easily report to entities and look at their work internally, in terms of how many kids have autism, intellectual disabilities, et cetera.

And... what kinds of services, I think, are they currently receiving?

So... my sense of it is, when VPDCA found out they got their grant, it was very empowering, but as is typical of our Asian groups, they're very humbled. So... they asked for ongoing technical assistance from us about how to do this for the next year. When I reminded them, they already got the infrastructure, that made them feel good. I'm going to stop it with this.

So that we can have a little bit of time for questions and answers.

>> Great, next we have Brenda Liz Munoz, a current bilingual community services specialist at the center for Leadership in Disability. Supporting families, children and youth with disabilities. Please join me in welcoming Brenda.

>> Brenda: Good afternoon, everyone, I want to do some acknowledgements and thank you for coordinate ing our webinar this afternoon

and also to my copresenters. I also want to acknowledge my director. The Center for Leadership in Disability, and professional mentors. Working for and with communities.

The Center for Leadership in Disability, much of you have heard of the ongoing progress on our teams being accepted. I want to give some context of how it came about. And... it was actually through the Office of Intellectual Developmental Disability that we were able to secure funding in 2018. I became the first at the center in 2015. (?) [Voice is very low and difficult to hear].

We started with three focus areas, which is collectives, and social impact. Leadership and education for families, as well as informal and formal advocacy.

So... some of our activities include our annual office expos. We co-plan and establish checks that are able to deliver content in Spanish or have the content delivered in English.

Throughout the years, we have co-planned the Spanish chat to align with the conference this year. Planning all activities, it was focus on addressing the various things. We're very fortunate to have Dr. Sandra McGonia who would be a keynote from Texas.

Other activities will include an educational group. It's a group that meets once a month, it's a partnership with the Veterans and support groups, which has been in Gwinnett County for over 20 years now. And for the past three years, we've had a base where the [indiscernible] community could meet to navigate the systems of care. This, we do in partnership with the CDC, as well as the Georgia Department of Public Health. We've become their outreach for the Latino community in metro Atlanta and beyond.

We received social marketing materials in Spanish that we go to health fairs, educational fairs, and... such, like... partnership at the consulate of Mexico and [indiscernible] development. So... campaigns might talk to your baby. (?) We have materials that emphasize the interaction of parents and child.

Other services include the adults and mental health aid curriculum. We have trained over 175 participants to include professionals and families on mental health. Any given day, I'm able to teach students, youth curriculum in Spanish. Or in English.

Others would include, Spanish, -- if you know anything about the centers for leadership and disability or anything about my director, he does process and behavior intervention support. [Captioner is having a hard time hearing the speaker]. Other activities that we engage in are... academic and professional interpretation. Which I have made this about. It means that I function as the interpreter. This provides an opportunity for us to take trainings and conferences and make them [indiscernible].

We have a network of professionals, families and allies. Early on, I dedicated time to get to know our community and have the community get to know us. We have developed a number of community practice partners to include the long -- I guess, the longest-serving non-profit. The Latin American Association, who we often partner with. And parent to parent in Georgia. We partner with autism centers and many professionals there. And... we also have families who now have emerged as their own group called familia [indiscernible]. Part of our efforts were to invest in parent leaders and for the past two or three years, we have developed a core of parent leaders that now have started their own initiatives and... would have the use of social media to promote events, to promote many of our events and to organize them so -- for... picnics, marches, they would promote health fairs, education, et cetera.

So... we're really proud of our familia [indiscernible]... our [indiscernible] families -- if I was to translate that. Other trends would be that we have, within Georgia State University created the Latina mentoring pipeline... which is an unintended consequence of my role. I have partnered with one of our colleagues at the School of Education to develop that. We have attracted Latinas that have observed as interns. We contribute and collaborate to our success.

Other strengths have been around the community's responsiveness. In the state of Georgia, the Latinx community is approaching if not exceeding 1 million [indiscernible]. Every single day, you have more administrations looking to serve the Latina population in Georgia. So...

I spoke, social marketing [indiscernible] -- in April. Fortunately, to collaborate with communication. With the Georgia Department of Public Health that are making their social marketing materials available to us in Spanish. Now... our challenges continue to be around access, for families... cultural and systems of care. Those other families use input to the state... you know, new to the state, therefore, their learning curve is steep and usually you have families that are simultaneously learning the disability culture and also, the culture of systems of care.

We continue to identify and securing funding -- there's an opportunity and support and... we are at task now, to make some of our demonstration services a fee for service. Particularly mental health first aid training.

We also have to take into account national and local issues that [indiscernible] and consultative meetings that immigrants and newcomers are using.

And social determinants of health. What impacts us all? Access to Health Care, medical insurance. Affordable housing. Nutrition testing and so forth. So... our families continue to be challenged by these issues.

Now... as far as lessons learned. I didn't include that, necessarily. In our slides... however... I must say that the Latino process initiative, for new ground... for further collaboration, for... development and some other service areas and support areas. So... lessons learned for you, lessons learned for us, continuing to think about how this work can be expanded. Expanded to other regions of the state, expanded in our scope and... the most impact.

And I will pause there.

>> Thank you so much, Linda. Now we have time for question and answers. Please feel free to type your questions in the chat box and I'll read them aloud for the presenters.

So... I have a question, this one is for Brenda. Can you expand a little bit on some of the more creative sources of funding to sustain the community of practice over time?

>> Great question. I'm -- that's just me chuckling by the way. We are in the process of, like I mentioned, our fee for service. Particularly your interpretation and capacity to be able to offer that. We offer technical assistance, so... and I have worked extensively throughout the network, throughout the year and in consultation, so... doing more technical assistance as well as providing an opportunity for fee for service for training. And for interpretation. However... needless to say, we're also looking at foundation and grant money.

>> If you have any additional questions, please add them to the chat box as well.

>> I'm interested in learning how findings from any of these demonstration projects have informed other core functions the the UCEDD, if any?

>> Fran: So... I wanted to respond that... with our project, because it does have a strong evaluation component, although... we are not necessarily looking at, at publishing, we have presented the data from the project and... so... that is tied in with our research core funding. As well as our professional training because... we are also looking at not only how we prepare parent partners for their jobs, but... also at the same time, looking at how we prepare agencies that employ parent partners to more-appropriately, use their skills. And knowledge.

>> Barbara: Our Vietnamese project, Franny is our director of community education, so... we consulted with her about working with the Vietnamese community. And... then, in terms of technical assistance and capacity-building, I, I think much of what we do, if it's going to be sustainable should be under that broader umbrella. Anything we developed with good information and it seems to be making a difference, has a, sort of a way of getting into the system.

>> Great... thank you so much. Thank you all for attending this webinar. This webinar has been recorded and will be archived in the webinar library. If

you would like anymore information about the UCEDD Resource Center, please feel free to contact us. Please take a few moments to complete our survey, thank you very much.

[Presentation concluded at 3:57 p.m. ET].

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