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RESEARCH BY UCEDDS
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>> Luis: Hello. And welcome to the seventh installment of our Coffee and TA series. Focusing on research. My name is Luis Valdez. I'm a program specialist at AUCD. We would like to thank you all for joining us today. Before we begin, I would like to address a few logistical details.

Before each individual program presentation, we will provide a brief introduction of our speakers. Following the culmination of all the presentations, there will be a time for questions. Because of the number of participants, your telephone lines will be muted throughout the call. You can submit questions at any point in time during the presentations via the chat box. You may send a chat to the whole audience or to the presenter only. We will compile your questions throughout the webinar and address them at the end. Please note that we may not be able to address every question and may combine some questions.

This webinar is being recorded and will be available on the AUCD webinar library. We will provide a short evaluation survey at close of the webinar. We invite you to provide feedback on this webinar and to provide topics for future presentations. As mentioned, we are hosting a multi-part series on the functions as categorized. We will start off with a quick overview of how this is mandated. Followed by OIDD's definition of research based on the model revised in twelve. We will have presenters from three different UCEDDs, addressing how their

program addresses this core function throughout program activities. We will then conclude with questions and answers.

Previously we held our first six installments on interdisciplinary pre-service preparation, continuing education, community training, technical assistance, model services and demonstration services. The archive is available on the AUCD library. This particular installment will focus on research. Here's a list as a head's up of the upcoming webinars planned in this series.

Section 153 of the developmental disabilities assistant and bill of rights act of 2000, the DD act, covers the purpose of activities to be undertaken by the national network of UCEDDs, outlining a series of core functions. Including a specific text of conduct of research which may include basic or applied research, evaluation and the analysis of public policy in areas that affect or could affect either positively or negatively individuals with developmental disabilities and their families.

That text was subsequently developed into the UCEDD research core functions. Further, OIDD issued a final rule on 7/15 implementing the DD act. In this guidance, OIDD mentions the need for each UCEDD to have a written plan for how each program implements the core functions. This will be a topic of a future installment in this series.

This is also further echoed in the UCEDD funding opportunity in which each applicant must provide a 5-year plan for carrying out the core functions as they are outlined in the DD Act. And finally, based on OIDD's logic model in which they provide clarifying definitions for each core function, the definition provided for research is as follows

>> Implementation of basic and applied research, program evaluation and analysis of public policy on issues impacting individuals with developmental disabilities. Very similar to the DD Act language. First, we have Elise McMillan and Robert Hodapp. Elise McMillan has 20 years of experience in projects that support individuals with developmental disabilities for families and communities. She holds leadership roles on numerous national and state organization. As co-director of the Vanderbilt Kennedy Center, she

provides oversight of daily operation and assists coordinators and others in functions of planning and implementation. Robert Hodapp oversees a research program applies in basic. They are conducted as part of the UCEDD. He develops the UCEDD research agenda along with the community advisory committee. Please join me in welcoming Elise McMillan and Robert Hodapp.

>> Elise McMillan: Thank you, Luis, for that introduction. This is Elise McMillan. I'm going to provide the overall framework for our center and turn things over to Robert Hodapp. I have to say, it's really good to be with you here today. I think when we were asked to do this about 2 months ago, none of us could have dreamed under the situations we'd be presenting this. But again, we're happy to be with you here today.

So, I wanted to provide a little bit of a framework. And also, for Kansas and Waisman, provide this kind of context. Because all three of our centers, in addition to being a UCEDD, are also an IDDRC and a LEND program. And I think as we go through in our presentations, you'll see what kind of wonderful framework that does provide in the context of research. So, for our intellectual and developmental disabilities research Center at Vanderbilt and at the Vanderbilt University Medical Center, that research extends all the of the colleges in Vanderbilt and led by Dr. Jeffrey Neul.

And we have a LEND training program like the other two presenters today. And I know it's the case in quite a few of our programs, Dr. Evon Lee is the director of our LEND. And also serves as the training director for our University Center. And, of course, LENDs are to prepare health professionals and educators to meet the needs of children and youth with disabilities.

Another aspect that really is instrumental in supporting the research at the Vanderbilt Kennedy St. Is our treatment and research institute for autism spectrum disorders. Many of you probably know Pablo Juarez, director of TRIAD, who is in a number of activities. Now to our specific UCEDD. We became a University Center in 2015. Which if any of you are doing the math, means that we are one of the three University Centers up for our 5-year renewal

this year. So, we've just submitted our next 5-year application.

Overall, this cube does present the context of our programs. So, at the Vanderbilt Kennedy Center, we have four areas of emphasis. Those include education and early intervention, employment, health and mental health and quality of life. And then you see we have the same four core functions as all the other UCEDDs.

The print maybe too small for you to read in this slide. And either at the end of this presentation or at a future time, we're very happy to answer questions about any of the work going on at our Center. There certainly would be research going on across the four areas of emphasis. And so, with that setup now, I'm really happy to turn things over to our director of research, Bob Hodapp.

>> Robert Hodapp: As you'll see, the LEND program TRIAD which is specifically related to autism is the UCEDDs. We all work very closely together. And I think that's really important. Because what it does for the Center is it allows us to do a whole lot more than any of us could do individually. And I think I'll -- you'll see that as I -- as I start talking here. The other issue is that we have a many, many things going. Elise showed you the cube. That's roughly 40 different programs. There are even sub-programs and all sorts of things as well. And again, they all go together. And I do think the synergy is really important.

The guiding principles that I think are important in terms of search is that we try really hard to embed research into all of our service and outreach programs. We probably do that better in some programs than in others. But I think we try to think research and we try to prioritize research. So, we try hard to make research not be sort of an afterthought.

The second issue here, which is, again, another guiding principle, is that we very intentionally involve our trainees in a whole bunch of different roles. And I'm gonna give you an example in a minute of how some of my doc students over the years have been involved in basically coordinating a program and also researching that program. Both. And we do that for a lot of reasons. But I think it's -- it's an -- I don't want to say untapped

source -- but a source of work and professionalism which I think is worth thinking about.

We also include a range of stakeholders. Including faculty. Both who are a part of the UCEDD and those who are not. Trainees of different levels. Including pre-docs, a few post-docs. Master's students. Quite a few master's students, in fact. And students who are not trainees, community members, persons with disabilities and their families. All of those stakeholders we try really hard to incorporate into the service and research enterprise.

And then the last part of that which also relates to some extent to the stakeholders is that we do this in collaboration with the CAC, with different community agencies. With state and local experts. I should mention that we have the good fortune, really, of being in the state capital in Nashville. So, we often have the home base of a lot of different agencies and experts. And we also are Vanderbilt. Which also helps.

The example that I want to spend the most time on is something called the Volunteer Advocacy Project, or the VAP. And the VAP is a 12-week, 3-hour week, so, a 36-hour workshop, for advocates to learn about special education law, advocacy and procedures. We have it at the Center. And it's expanded to 6 to 9 sites throughout Tennessee. Essentially, I'll show you a map in a second. But what started really in one small conference room has now expanded out to 6 to 9 sites across the state. And includes different each year, but roughly from 60 to 80 people who go to each of those 12 weekly workshops. This year it is spearheaded and directed by Brittney Gosicki. Brittney is my second year, soon to be third year doctoral student. She's a former teacher. She's very interested in education, in special education. And she's done a great job of spearheading this.

I wanted to spend a minute about the history because I think that's kind of important. We started in 2008 with Meghan Burke. She wasn't the first of my doc students, but one of the early doc students. And Meghan was a long-term UCEDD trainee for the five years that she was a doc student. And Meghan herself is a -- an older sister to a young man with down syndrome. Her family had trouble getting

services. And she wanted to start an advocacy project. She went out. She researched what different kinds of programs there were, and she essentially developed this. She herself ran it. She was the director of it from 2008 until she graduated in 2012.

Since that time, we have -- when she ran it, it was twice a year. We have since been able to get our act together once a year in the fall. And so, it runs every fall from late August until the middle of November. And to participate, an applicant fills out an application. They do a pre-test and a post-test. And the pre-test and the post-test are the same. The pre-test and the post-test both relate to knowledge of special education rights. It's essentially a 30-item multiple choice test. Pretty hard, actually.

And then the second part of it has to do with what I'm gonna call skills and comfort. So, to what extent do you feel that you are skilled in advocacy, in dealing with your school system, or a school system in terms of a child's educational rights? So, what extent do you feel comfortable doing that? And attendees fill it out before the first session and after the last one. And then what we do further on over the years kind of after they've left is, we also ask if they have advocated for others, what they done and things like that.

And so, in terms of the participants, they agree before they start to advocate for four families. Many of these are parents or family members. About 70%. We also have persons with disabilities. We have some teachers. We have some other professionals. We have some graduate students.

And, again, so, and -- and then I should -- I did mention that the -- it's done in Nashville and throughout the state. And if you look, you are looking at a map of Tennessee. You'll notice the black dots who are the attendees are primarily based on the bottom left-hand corner in Memphis. In moving to the right, our site here in Nashville. Bottom left is Chattanooga. Moving further to the right, to the east, is Knoxville. And way out there to the way northeast is a place called Tri-Cities. And we have had distant sites in all of those places with the exception of having it here live.

And those are where people are essentially

being trained. The topics. Each week there's a set of topics. They run the gamut of all sorts of things in special education. Having to do with introduction to IDEA, disabilities covered, assessment, eligibility and evaluations. Functional behavior assessment. Early -- part C, person-centered planning. There's all sorts of stuff that gets done each time. Each time it is essentially the same. We do update the slide -- what we're presenting a little bit. The presenters are professors from Vanderbilt. They are people, knowledge, often from state agency. They're people from DLAC, the lawyers. They're from various different groups. And many of the presenters are -- present many years. So, they've done this before. They do update their slides every year. But generally, it's the same -- most of the same presentation.

In terms of the directors, the directors are one or two of my doc students. And my doc students have been Unbelievably generous with their time. They are doctoral students. They're doing courses, they're doing research, they're doing all sorts of other things. I wanted to name them because I think it's kind of important. Meghan started it. And was the guiding light for five years. She's gone on to the University of Illinois and she does versions of the VAP in there and in other places. Samantha Goldman, Maria Mello, Kelli Sanderson, Ellen Casale and Brittney Goscicki is the latest.

They are assisted by a couple of master's students. Every year I have anywhere from three to five new master's students. And they also help out a whole bunch of ways. The work that is involved involves recruiting. We send out all sorts of emails and calls to different disability agencies throughout the state. Usually a couple hundred. They have to oversee presentations. They have to get the technology running. They schedule and oversee the updating of lectures. And they attend and present at, particularly the director, present at one or two of them as well. So, there's a whole lot of work that's involved here.

In terms of over the years, what we have been able to accomplish. We have -- I've kind of broken them up into a couple different kinds of studies. The first one was essentially a pre/post study on does this

work? And we basically showed that the attendees at the VAP for the first couple of years showed more knowledge. That 30-item questionnaire I mentioned. And authority in advocating. We've recently looked although a little more what other things are changing. And we're finding that things like empowerment and feeling in control of the process is changing for parents and advocates.

We have also looked at advocates. Now, this is that entire group of people who have gone through and attended and graduated from the VAP. We wanted to know who is it that is continuing on and advocating? And remember, I mentioned one of the costs, if you want, of attending the VAP sessions is that you promise to advocate for four parents. Or for four families. Well, turns out that we don't really enforce that. We do ask that the people do it. Some people do it, some people can't do it.

And what we found is one of the big predictors was one's self-image as an advocate. And the other one had to do with kind of being a part of the disability community. And so, we've thought a lot about that. And we've thought about what is it that helps people to have a -- the -- not just the knowledge, but also the image of wanting to be an advocate and to continue advocating.

We also have, and this is Meghan and Samantha, have done some things on looking at the advocate experience. What the role of the advocate and how it works and what are the kind of steps in advocacy. We've also begun to look at parent experiences. One of the things that's happened is over the time, various people throughout the state have realized there's this whole cadre of trained advocates. Recently we have partnered with the Arc. The Tennessee Arc. And the Tennessee Arc is taking the VAP advocates and doing a better job of placing them with parents and families that need advocacy.

But while they were calling us, we kind of made a lot of that. We found out who are the people that are calling? And one of the things that we found is it is more often parents of children are autism. We asked, what do they -- why do they -- what are they calling about? We followed up and we asked what happened? How they saw the advocacy process.

All of those kinds of things. So, we essentially -- we moved from, does program work and what is the perspective of the advocate? To what are the perspectives of parents calling in for advocacy?

And Meghan and Samantha have also done some things looking at culturally diverse families and how the special ed process works for them and what are their special challenges and needs. And so, and there's actually even a few other things besides that. And so, essentially what we're trying to do is to look at this VAP and its sort of outgrowths in a bunch of different ways.

The other thing I should mention is that we have started to do what I'm gonna call an extension. put the word in quotes because I'm not sure it's exactly an extension. I think when we started this. And the we here is Julie Lounds Taylor, another faculty member, a UCEDD faculty member. We thought that this would be just a similar kind of thing. Taking the VAP and we did hold to the 12-week, 3 hour a week model, if you want. But the content was totally different.

And the content for the VAP-T as he was originally called, now it's called something else, is that we took the model and we extended it to parents of adolescents and young adults with autism spectrum disorder. And the reason I put the word in quotes was that the content was totally different. And in fact, very, very hard to get one's hands around because both services are so disparate. They're so disconnected. There are differences in housing and in employment and in post-secondary ed. And trust and all sorts of different kinds of things.

And so, it very much was different in some ways. We piloted it in Tennessee and then what has since happened is that Julie and her colleagues, including some at the Waisman, have -- and Meghan in Illinois -- have begun to extend this to different states.

So, we've taken the model, but now it's kind of individualized, if you want, to different states. So, now what I want to do for a minute and then Elise is gonna kind of wrap up here is talk little bit about the lessons learned. And to me, the lessons are several. One has to do with involving multiple stakeholders. We could not do this without the unbelievable help of

the trainees. They put in countless hours recruiting, getting the slides to the presenters, making sure everything is gonna work. The CAC has been a partner involved in this all along.

Our community members, both in terms of getting the word out to people, the agencies that have given up their time who have helped us out. The Arc that is now doing the follow-up. Tying our graduates to people who need the advocacy. Parents, families, advocates. An entire set of people here that have done just an incredible job in countless ways.

Another strength that we have, and I don't want to minimize this, is an infrastructure. We have an incredible staff at the Kennedy Center who have just been invaluable in countless ways. And the fact that we have and work very closely with IDDRRC and the LEND and TRIAD, we've called on many, many of these people to present, to help us out. To work with the technology. All of those kinds of things we have. We have a research university. We have lots of different people who can speak on applied behavior analysis. Who can speak on any number of kinds you have things. We have a cadre of researchers in training that are really interested in disabilities. We have a very strong local disability community that really hangs together well.

We have space, we have equipment. We have distance capabilities. We have all of those kinds of things. And then other thing, which is not minor, is we have something that many people are interested in. What -- when I mentioned how in 2008 it -- the VAP was in this little room with 10 people. And now it's 60 to 80 people. 15 or 20 of them who are in the room. And others who are dispersed across the state in 6 to 9 places. That is a testament to the interest in the community for having this kind of thing.

A second related issue has to do with people. I have been blessed over 12 years with unbelievable trainees. Elise and I in preparation for this webinar mentioned how these people are wise beyond their years. They are somewhere in the neighborhood to 25 to 32. And they are taking this thing and they're going with it and they're teaching each other and they're doing a phenomenal job. The community partners recruit for us, join us, present for us. Over

the years, we've had over 500 attendees. A large majority of them come to every session. Three hours. Some years it's from 6 to 9:00 at night. Other years it's 9:00 to 12:00 in the morning. And we've got that kind of working well. Collegial, all sorts of things like that.

And then the weakness I want to talk about. I see my time is going to go here a little bit. Has to do with this is an unbelievably low cost operation. We are doing this with just basically payment for registration and for the binder. There's a couple hundred page bind their you get with everybody's slides. We always wonder, can we keep it going? The research operation is also done on the cheap. We are taking those questionnaires. We're doing things with very, very little money. A lot of interest. And particularly the directors and researchers, that's what they're being trained to do. So, they're really interested in it. But we have some challenges.

The recommendations for me are that one, try hard, always, to blend service and research and service and outreach. I think sometimes there's a difference in mindset between researchers and service delivery people. And I think we've tried really hard to try to -- to blend those two things. I think that everybody benefits from determining if, how, when, how much and in which way the service works. And then the other thing I would mention is that it is important to adopt what I'm gonna call a research attitude.

Does a program work? How does it work? Why does it work? What is program success on others? What are the short-term and long-term effects? And is there any little tweak that you can make to make something more researchable. I mentioned program for Julie, we made it a wait list-controlled design. When people come you, they either take it now or a year from now. And they are randomly assigned. The bottom line is, everybody takes it. But because we do that, we are able to do certain studies. Sometimes we add measures or add little tweaks to make it more researchable. But you have to think about that on front end.

I think research is important. I think it's as important as all the other UCEDD core functions. And I think it -- it's important to value the research of

the enterprise. And with that, I'm going to turn it over to Elise to finish up for a few things.

>> Elise McMillan: Great. Thanks so much, Bob. And you see why Bob is -- it's so wonderful to work with as our director of research. In the interest of time, I'm gonna hit highlights on the next couple of slides and happy to answer questions at the very end or you'll have my email to follow-up. So, for today's presentation, we chose to go deeper into one research project. There is multiple other projects going on across the Center and I wanted to mention just a couple of things also that we are -- have going on.

We have a number of studies looking at the impact and use of telemedicine and telehealth in education and health care for people with ASD. We are looking at the effective transition interventions for students moving from school to the community. And we're also looking at increasing the capacity of communities to include people with disabilities engaging new partners. And those would include employers, congregations and community leaders.

So, again, Bob hit on some of these. But we were asked to talk about some of the challenges and then suggestions. So, Bob and I talk about this a little bit differently, I think. But we are at a center where there is a culture of research. And we have been very lucky that we came in as a UCEDD after we had already been a research center for 50 years. I think you always have to be appreciative of the time. So, no matter if you're working with faculty, trainees, staff and others, you're probably not the only project, the only thing they have going on. And the more that you can make it workable for, especially for the trainees who are also students or other faculty members, the more successful that you can be.

And then, of course, funding. We'd always like to have more funding for research. In terms of recommendations for other UCEDDs, some of the things that have worked well for us -- and again, we would be happy to share with others -- are to partner with other UCEDDs. We just started a partnership with Virginia Commonwealth University on two Nadler-related employment and are very excited about that opportunity. Through our higher education program, next steps at Vanderbilt, we've really had

the opportunity to partner on research projects with faculty who are outside of our UCEDD in other parts of Vanderbilt University. Some of these are looking at things like universal design.

And also, then, what happens? What's the impact of students without disabilities having students with IDD in their classes? We found real partners for research in terms of our own developmental disability network here in Tennessee. Tennessee is one of those states that has two university centers. Many of you know Bruce Keisling who heads the University of Tennessee UCEDD. Our UCEDDs have partners on an IDD toolkit projects with our disability rights Tennessee. We've done a number of projects in the area of supported decision making.

And then with our council on developmental disabilities, the council has had a longstanding interest on how you effectively share information with people with disabilities and their families. We have a project called Tennessee Disability Pathfinder. And in fact, we're just launching another evaluation for that project. So, even within your own DD networks.

The other thing I wanted to mention is if there are only, I think, 14 IDDRCs. So, there's certainly not going to be an IDDRC in every state. But I think those UCEDDs that don't have an IDDRC can reach out to IDDRCs in their region. Or maybe IDDRCs that have a similar interest or for whatever reason want to work with your state. And we would be happy to connect you if you're having trouble making those kinds of connections.

So, with that, that's our connect information. And I think now I will pass it on to Kansas for their presentation.

>> Yes, thank you, Elise, and thank you, Robert. Next, we have Evan Dean, Sheida Raley, and Tyler Hicks. And Evan Dean is at the Kansas University Center on disability disabilities. Researching effective methods for community participation for people with IDD through enhancing supportive decision making and career design. Sheida Raley is a doctoral candidate at the University of Kansas in the department of special education. And a graduate research assistant at the Kansas UCEDD. Researching assessment and promotion of self-determination for all students. Including students

with extensive supports. Tyler Hicks and an assistant research professor at the University of Kansas and a director of qualitative research of methodology at the KU Center for Disabilities. Join me in welcoming Evan, Sheida and Tyler.

>> Hi, everybody. As Luis said, my name is Evan Dean. It's great to be talking with you about research and some of the research projects we have going on at the University of Kansas. As he said, I'm the associate director of KUCDD, the Kansas University Center on Developmental Disabilities. And my particular focus is on establishing and enhancing our community partnerships and services.

So, for this presentation, I'm gonna talk about two particular research projects that really exemplify our UCEDD partnerships with both the Kansas IDDRRC, our LEND program, and also our various community partners.

And as Luis said, my co-presenters are Sheida Raley who is going to highlight a couple of other projects that really highlight our partnerships in schools and our research in schools. And also, Tyler who is going to -- I think one of the big challenges that our Center has is as we've really grown our research profile is, you know, how do we organize all of the -- the statistical analysis and all of the, you know, really data-intensive aspects of the research projects. And Tyler's been great at working through those projects and is gonna talk more about that.

So, as I said, we're at KUCDD, the UCEDD for the State of Kansas. And as Elise said, the University of Kansas is one of a hand full of states that have both a UCEDD and IDDRRC and a LEND program. So, the picture on this slide is of our community advisory panel. Which has members from all of these centers. As well as we have strong partnerships with our self-advocacy groups in the state and also our DD Act partners. The Kansas council on disabilities and the PNA, the disability rights center of Kansas. So, all of those contribute to our community advisory panel.

KUCDD has a long -- a distinguished history in research-related self-determination which serves as the basis for most of the work that we do. And the projects that we're gonna be highlighting today use that self-determination framework. As I said, we

have also strong partnerships in the state with our DDAC partners and self-advocacy groups and long histories of close collaboration. And the thing that I think is really great about this is that it really allows at least part of our research agenda to come from the needs of our disability community in the state. And then in a second, I'll highlight one project that has risen from those needs related to supportive decision making.

So, while my team focuses on enhancing community partnerships and services, we do this in service -- we're a research institution. We really do this in service of our UCEDD research agenda. Our primary research focus is on enhancing existing self-determination knowledge to support health and participation for people with intellectual disability.

So, our kind of overarching research question for our group is: How can we support people with intellectual disability to live the life that they want to live? So, my team consists of self-advocates that are on our staff. Parents of people with disabilities and researchers who have director experience living with a disability or supporting people with disabilities.

So, you know, it's really great to be working with a team like this. Because these experiences really inform our work and drive our process and our innovation. So, and what these experiences have shown us that I don't think will come to us as a surprise to anyone here is that the participation of people with disabilities is affected by complex contextual factors which are generally outside of the control of the person. Like, you know, federal and state policies, the training that care givers receive and things like that.

But also, that the more ability and opportunity that a person has to advocate for themselves and direct their services and supports, the better they can control these contextual factors. So, given the complexity of this problem, we're taking a multilayered approach to our research and intervention development. Which is shown here.

So, and I'm gonna highlight two projects. One that kind of focuses on the context and the human experience. And another data-driven analysis to further theory and intervention development.

So, just to kind of reiterate. So, living the life

that we want to live involves a lot of decision making, a lot of planning, goal-setting, problem solving which are all skills associated with self-determination. And historically people with intellectual disability haven't had the opportunities or supports to develop these skills and have lived in contexts that undervalue their potential and hold low expectations regarding their contribution. But we also know that not only can these skills be learned, but people who possess higher degrees of self-determination have better participation outcomes in terms of employment and community living. And also, higher quality of life.

So, our first project focused on the context and human experience. It is a -- is a partnership between our UCEDD, our DD Act partners, self-advocacy groups in the state and family members and older adults. And we're really focused on better understanding the supports that older adults and people with disability use to make decisions in their life.

I'll say more about this in a second. So, right now I'm just kind of giving a high-level overview of these projects. And then our second project is a partnership that leverages the medical informatics and data analytics of our IDDRRC and the community partnerships of the UCEDD to use a data-driven approach to understand the relationships between health, community participation, self-determination, and self-determination from people with Down's syndrome.

So, for our supportive decision making projects, we're conducting focus groups across the state of people and their families to better understand the supports that people use to make decisions. And the ideas that we're gonna use this information to -- to develop and pilot a planning process that can be -- that can be used by people with intellectual disability and their families to develop those and find the supports that they need to make decisions.

So, this research is funded through a couple of places. One is the Kansas Council on Developmental Disabilities and also the WITH Foundation. So, this is going to inform our intervention development related to supportive decision making for self-advocates and families. As we see the intervention to promote decision making

as a way to empower people to direct their life and enhance their overall self-determination.

This intervention work also informs our state-level planning process that the UCEDD is leading as part of our ACL-funded supportive decision making planning grant. And this project, as noted earlier, involves our community partners and national experts in supportive decision making at other UCEDDs. And will culminate in a long-term plan for the state to enhance practices of supportive decision making.

So, then our other project that I'm highlighting here is a data-driven project with the Kansas IDDRRC. Which is a supplemental project, DS-include. So, it's a collaboration with the bioinformatics team at the University of Kansas Medical Center and other partner sites around the country. So, this project takes a large data approach to understanding the relationships between health participation and self-determination in people with Down's syndrome. Through linking data from electronic health records, DS-Connect, a national registry for people with Down's syndrome, and the inventory developed at KU CDD. This will help us understand between health participation. And guide future development related to health promotions.

So, this partnership with the IDDRRC has been great. Both in terms of this project, but also in connecting health data across other projects that we're working on. So, we're really excited about this partnership. And what it's gonna mean for the future. So, next I am going to turn things over to Sheida who is going to talk about some of our self-determination projects in schools.

>> Sheida Raley: Hi, everyone. My name is Sheida Raley. As Luis mentioned, I'm currently a doctoral candidate in the department of special education and also a UCEDD trainee at the Kansas University Center on Developmental Disabilities. What I'm going to share with you today is some of the research we conduct in partnership with schools to enhance the outcomes of students with disabilities related to self-determination.

I'll talk about three different projects we have going on to give you a good overview, like a broad perspective, of the different types of research that we

engage in. Including intervention research and then I'll also talk about an intervention development project that we have going on. And finally, I'll talk about a measurement project. So, focused on a measure of self-determination that Evan actually referenced when he was talking about supportive decision making.

So, the first project that I'll talk about is one of our large-scale research projects we have going on to really look at how we can promote student self-determination when students are learning in inclusive general education classrooms that are focused on core content learning.

So, this project takes place in multiple high schools across Maryland and Delaware. It is a longitudinal project that is taking place over three years. So, we're currently in our second year of implementation. And this project includes a cohort model. So, it includes ninth, tenth and 11th grade students throughout the three years of the project. But in the first year, which was the last academic year, we focused on ninth grade students and then this year we followed those ninth grade students into tenth grade.

And then next year we'll follow those tenth grade students into 11th grade while taking on a new cohort of students from the previous grade. So, by the end of the project, we'll have three years of students that have engaged in an intervention to promote self-determination to really look at those changes over time as self-determination as a developmental construct that takes time for students to really build as they have more opportunities and experiences. And their teachers really learn how to promote self-determination as well.

I should mention too that this project is funded by the Institute of Education Sciences. And the intervention that we use in this particular project and much of our work at KUCDD focused on self-determination is the self-determined learning model of instruction. So, I don't have the time to go through it as deeply as I would love to, but it's an evidence-based practice to promote student self-determination by supporting students to go through a self-regulated problem solving process in which they set a goal. They create an action plan to achieve that goal and then they reflect on what

they've done and decide if they need to adjust that goal or plan.

And I'll -- we'll give you a link to our website if you would like to go and find out more information and also our contact information so you can always email us if you have more questions after this webinar.

But in addition to looking at the intervention impact in this project, we're also looking at what kinds of supports do teachers need in order to support their students to engage in self-determined action? So, in this project, teachers are randomly assigned to two different levels of support. One in which teachers receive online modules that are pushed out every two weeks.

That support them in their implementation, but they're not interactive, per se. But they're pretty low cost in terms of their -- the implementation support. The other group of teachers receive those same online supports every two weeks, but then they also receive monthly in-person coaching from trained coaches from our partners at the Maryland Coalition for Inclusive Education which is thinking about sustainability would be a higher cost implementation support. So, we're really wanting to learn what are the differences in the impact of those supports on student outcomes and teacher outcomes. So, then we can provide guidance to schools in the future of if they're going to implement an intervention and include the context to promote self-determination, what kind of supports do they really need to have in place to ensure that it's going to be successful and implemented with fidelity?

I should mention, too, that like Elise mentioned, we are very fortunate to have our UCEDD, a LEND and an IDDRC in Kansas. And we've had some fantastic collaborations across our three entities to develop some of these implementation supports. Particularly we've had a lot of integration of LEND trainees that have an interest in self-determination. And they really supported some of this work on this project as well as others too.

The outcomes that we're looking at in this project include student-level and teacher-level outcomes. So, we look at how does self-determination change over time? Academic

achievement of students with and without disabilities. And then also, access to general education curriculum for students that receive special education supports and services.

With the intention that we would hope to see higher post-school outcomes. Including post-secondary education enrollment, competitive and integrated employment and community access and participation. On the teacher side, a couple areas that we like -- that we were looking at is how does engaging in this intervention enhance teacher knowledge and skills to promote student self-determination? And what's their fidelity of implementation with the supports that they receive? And does that vary depending on the support that they receive to implement the FPLMI?

The next project that I'll talk about is one that we have going on currently to develop a goal setting app to support students in promoting self-determination. This is an interactive web application. And it's built on the same framework as the self-determined learning model of instruction. But the key difference here from the previous study that I talked about is that this app is really designed for independent use by students with high incidents of disability to enhance their goal setting and attainment skills.

So, teachers are involved in the process as they support students to really think about the goals that are important in their lives and think about how they want to take action to those goals. But the app really supports students in self directing that process instead of really the teacher being the driver of implementation.

So, this is another project that's funded by the Institute of Education Sciences. And we've conducted focus groups with students with high incidence of disability as we've developed the app. We engaged in user testing to really look at the usability of specific components. And then this current academic year we engaged in single case design studies to really look at some of the impacts that on a small scale. And then next year the plan is to conduct a small pilot study with a sample of students across two different states that are learning how to engage in self-determined action, but then

doing so with this goal setting app.

And then finally, the last project that I'll talk about related to self-determination that we work on is one of our measurement projects. And this involves a validated assessment of self-determination that we developed at KUCDD for students with and without disabilities aged 13 to 22. And then also we have another parallel version for adults.

This assessment is not only used as a transition planning assessment, but it's also used to guide instruction and support teachers and students as they collaborate to figure out what kind of supports are needed to enhance student self-determination. This measure is 21 items and it takes approximately 10 minutes to complete. And it also includes some online accessibility features like in-text word definitions, audio playback and it's compatible across mobile devices and tablets. And we use it at our UCEDD to collaborate with schools, districts and also state departments of education so they can look at across their school district or across the state how does student self-determination change over time? And what are some areas of need that we need to adjust our supports and instruction to promote student self-determination?

And currently we're planning to create an even more accessible version for students that might communicate in a diverse method of communication. For more information, you can go to our website which is [self--determination.org](http://self-determination.org). And it will provide some information as to that. But I will turn it over now to my colleague, Tyler Hicks. He'll talk a little bit more about our research infrastructure related to our statistical team.

>> Tyler Hicks: Thank you, Sheida. My name's Tyler and I'm the director of qualitative research methodology. And part of the fun that we have working in the field of disability studies is that there are a lot of opportunities to be innovative in our methods to further the field. And so, working across projects that we've got ongoing, as my colleagues have described, we've had the opportunity to develop a team in which we use a project management approach. In which we employ about two or three individuals.

Postdocs, doctoral students and myself to

provide mentorship which we're helping qualitative methodologist learn the intricacies of research in developmental disabilities. But also, we work together as a team. And we each have sort of different diversity of skill-sets that we often bring to projects. And that often helps when we encounter challenges like we have small numbers to deal with. That we've got a need to call with some sophisticated measurement to actually track the outcomes that we care about. How do we do this?

And so, as a team we are often involved in a lot of different meetings and other investigators. Projects and help in some addition making. And some of the services that we offer as a team and how they play out, I would love to get three basics. The first would be data validation. And in the field of open source, in the era of open science, I should say, the qualitative data can be more important. Because there's more requirements for researchers to publish the data that they've based their analysis upon so that other researchers can re-create those analyses.

To make sure our data is as high quality as possible, we have automation routines to clean the data to make sure that the data reporting is standardized. And we often will have two people independently replicate the same data-cleaning procedure to make sure that there is convergence. And by doing that, we have a level of quality assurance that the data we're reporting can be trusted. And to facilitate the sharing of this research, we often, when we develop automated programs and create codebooks that are aligned with whatever the state of the state of the data is. If we were to share this data, other researchers and investigators could know what the contents of the data is, what are available, how we code it, what they mean.

We also give a user guide which describes the study and the project that the data origin that the from. It was a randomized control trial? Was it an observational study? And they can get the details to help them plan how to use it. And user cans request data from our website.

The other type of, then, the last bit I say that we often find ourselves helping but is grant support. In terms of -- for securing new grants, we perform a lot of power analyses to figure out the optimum design

for the study that's both feasible and informative. As well as we offer consulting and we actually run the analysis for projects that are funded in-house. So, we can run analysis and talk to the people who are the lead investigators so that they can be back and forth to make sure that the answers that are there are directly answering the questions they care about.

There are some of the infrastructure components that we have built up in Kansas to help advance research. And with that, I think unless my colleagues want to add anything, I think we're ready to turn it over to the next group.

>> Student: Just to wrap it up on Kansas. Some of the challenges and recommendations that we would like to leave everybody with. So, some of our challenges are competing project demands and only so many hands on our research team. Also, managing a growing research team has been a challenge. But successes that we have experienced and that we recommend are strong partnerships with other organizations. Like self-advocacy organizations, our IDDRRC, like Evan mentioned, and State Departments of Education. And also, consistent opportunities for communication, collaboration and innovation that are incredibly important. We do those through regular research team meetings. And also, diversity in perspectives. So, including people from diverse backgrounds and then absolutely people with lived experience that we can learn from and really move the work forward.

So, our recommendations are very similar to those from Vanderbilt. So, develop mutually-beneficial relationships with other Centers or groups. And ensure that there's dedicated time to innovating and collaborating as a team.

And for more information, you are welcome to email us. You can also go to our website for more information about self-determination or our UCEDD Facebook and Twitter pages. Thank you.

>> Thank you.

>> Thank you, Evan, Sheida and Tyler. Finally, we have Anne Harris. Anne Harris is the director of the Waisman center in Wisconsin. And serves in a collaborative, administrative role within the clinic's. Participating in the executive committee and working with the staff and clinic leadership to integrate

training and research activities into the clinics.
Please join me in welcoming Anne Harris.

>> Anne Harris: Hi, thank you, Luis.

I'm -- whoops. Now I know I can advance my slides.
So, just a little bit of an introduction. Again, I am the
LEND director at the Waisman Center. LEND is part
of the UCEDD program. And also, am the training
coordinator for pre-service and continuing education.
And I'll explain a little bit more about how our core
functions are aligned.

But I do want to just say that Elise and Evan
gave a little background on the idea of having a
Center that has all three programs. IDDRC, the
UCEDD and LEND. And we're one of those
programs. In fact, we're all in one building. This is a
little picture of the Waisman Center and to remind
everybody that we are in Wisconsin. At the
University of Wisconsin-Madison. That's also -- we're
a large research university. But it's important in the
context of our partnerships we're also the state
capital.

So, what I'm gonna do today is talk a little bit
about the context for our UCEDD research programs
and provide a few examples of -- which demonstrate
the focus on partnerships and collaborations. Some
of which have been discussed. But really seeing that
as sort of the foundation and the difference that it
makes our UCEDD research maybe a little bit
different than the IDDRC research.

I have worked at a couple of other programs.
I worked at both the UCEDD-LEND programs in Los
Angeles at USC and UCLA. And the reason I came
to the Waisman Center was because we did have the
IDDRC in there as well. And I wanted to strengthen
the integration and translation of research with the
clinical training and outreach activities which are our
other core functions.

So, the Waisman Center as a whole has a
mission to advance knowledge about human
development, developmental disabilities and
neurodegenerative diseases using these four core
function areas. Which go across all of our programs.
So, the IDDRC, the LEND program and the UCEDD.
But for the Waisman Center, the IDDRC does focus
more on basic research. And the UCEDD research
is more applied. So, that's another one of the things

that I wanted to introduce.

But there are researchers, investigators, in both centers. The UCEDD and the IDDRRC. That do both. So, it's not like a hard line between applied and basic research. But the IDDRRC is more focused on basic research. And so, our UCEDD research is really more applied and based -- and community-based.

In fact, when I came to the Waisman Center about 12 years ago, I was -- I was struck by the four guiding principles that we have continued to use as the foundation for all of our core functions including research. And for some reason, these four were just very easy to remember and they're foundational to, again, all of our -- all of our programs. Family and person-centered care, community inclusion, interdisciplinary approach, and the use of evidence-based practice. Or the development of evidence-based knowledge to inform practice.

And some of the terms have changed a little bit over the years. And we're using interprofessional training and other kinds of words. But it's really the foundation has stayed the same. And I think all UCEDDs have a similar type of mission and the same mandate in terms of our core grants. But these four guiding principles have been extremely helpful in keeping our focus for all of our core functions on what we're all about.

In addition, the Waisman Center UCEDD has areas of emphasis. Which I think somebody else mentioned as well and it was clear from Kansas about self-determination. But the ones at the Waisman Center UCEDD are a strong focus on health and health care. We have a large set of clinics. We have a focus on early childhood education with an active inclusive preschool. We have a focus on transition to adulthood with several projects. And in general, on community living.

And you will see these areas of emphasis reflected in the types of research projects that -- at our UCEDD which I'll be describing briefly. But again, the main point is that our research is applied, and it really relies on community engagement and collaboration. And this is included increasingly over the years. The involvement of individuals with intellectual and developmental disabilities at all levels.

All of our program development. Clinics, training, our outreach activities. But our research as well. So, our community members, including people with disabilities and their families are employed at the Waisman Center in leadership roles. They're part of the infrastructure for our training, research and service and outreach programs.

And we really wanted to say that because of this, we -- our work is embedded and is included or grows out of these collaborative relationships we have with the families and the agencies and the other programs in which our staff and the people that we serve are participating in. We have research strength in methodology related to public health and epidemiology. We use quantitative and qualitative. We have methodologies and have researchers are expertise in those areas.

And we also include in this general umbrella of our research core function areas evaluation research, quality improvement activities and policy analysis. Which I think was mentioned at the beginning as part of our UCEDD mission. But we really do quite a bit of work in those areas. I'm not going to talk about some of the ones that are not pure research. The examples I'm gonna go to now really are examples of research projects that have or have had funding that require IRB-approved protocols. And these are listed on our website if you want more information.

But I'm just gonna -- not gonna go through these in detail. But I wanted to give some examples of the type of applied research that our UCEDD is doing. And then if people have questions or want more information, we are happy to provide that in a different context. So, our -- and the contrast with some of the quality improvement and public health research that we do doesn't always have separate funding. But using some of the same techniques.

We also do clinical research, which is not listed here. And, again, those are often partnerships with some of our health care organizations where we aren't necessarily the lead. But we're a collaborator. And this list reflects the projects that are housed at the UCEDD or we claim as UCEDD projects.

So, the first one -- several of them are multi-year decrease. But the first is the longitudinal study of Wisconsin adult long-term care supports.

You have that the PI is Leeann on the call, DeWalt, our UCEDD director. And it's a multi-year survey of adults with intellectual and developmental disabilities accessing long-term care services. The second one is the assessment of early interventions outcomes, our AEIOu for children who are deaf and hard of hearing. This is a multi-phase study which we finished data collection for. But involved children enrolled in early intervention and diagnosed early with hearing loss. I'm the PI on that one.

Leann DeWalt is also on the transitioning together related programs. Which started as a psychoeducational intervention for families with an individual with autism spectrum disorders. Forgive the abbreviation, ASD. And has been successfully adapted in a number of different settings including schools and for Spanish-speaking families.

Another project, the evaluation of developmental monitoring using the learn the signs act early, our CDC educational materials in a couple of different settings including childcare and early head start. Gale was on that work. And then the last two listed for our UCEDD is the involvement of Maureen Durkin, the PI for both of our -- we're one of several ADDM sites and the SEED sites. That's for the autism developmental disabilities modeling network. And the early development in autism or SEED decrease. And Maureen Durkin is one of the main researchers with the public health focus.

So, a couple of points that I wanted to make about these projects, which is why I went ahead and introduced them. But, again, I'm not going to talk in depth about their study protocols. But I'm sure the PIs would be happy to talk about them although some other time. But really to emphasize the major collaborators that have made these projects possible. And in many cases, I won't read them all, but these are State Departments of Health, Department of Ed. There are other LEND programs, other UCEDD programs. We have a lot of partnerships with schools and counties, I will say.

So, some regional and some local partners. The EDHI program, the early hearing detection and intervention program and the birth to 3 program, which is our early intervention program in Wisconsin. And then we have national partners. And many of

our programs because they are -- our research projects because they are public health. Links with CDC, the Center for Disease Control. Whether it's funding or just a partnership in terms of the learn the signs act early materials or something like that.

We also partner very heavily with disability-serving organizations. We do have a constituency advisory committee that advises our -- our research efforts that participates in planning and for grant applications and informing the work. We have some work that's in partnership with our IDDRRC where we're actually looking at co-researchers for people with disabilities participating in all levels of the research as co-researchers.

And four of these projects have a strong emphasis on autism. And so, we have a lot of connections with autism communities, societies, people with autism and that's been a major focus of our work in the last few -- last 10 years or so.

The second point besides the sort of external collaborators I wanted to make was our internal collaborations. And our LEND faculty are active in the research. That's part of the interdisciplinary or interprofessional approach to research. These are just examples of trainees that have been involved specifically in our projects over the last few years.

Some of these projects would not have happened without the LEND trainee engagement, involvement from the initial part and have changed and been better because of them. So, we find the LEND trainees can learn research skills as well as enhance the experience and expertise that's applied to each project. So, again, thank you for the other presenters who called out the essential role of including LEND trainees in our research projects for the UCEDD as well.

And to wrap things up here pretty soon. The last point I wanted to make about the way we're doing research is our increased emphasis in our last 5-year UCEDD grant to look at dissemination and not -- specifically knowledge translation and disseminating research results to different audiences in different forms. So, of course, we've always had research reports or articles of peer-reviewed journals. Presentations. I meant to use state, local and national conferences. But the real thing for us is to

focus on sharing our research results with audiences that might not otherwise access research in maybe a different format. So, we now have a series of briefs. Some of them are -- many of them are issue briefs on our UCEDD website where we're really looking at what is the reason that we did a -- what is the key point that we want to share and what can people use from this research?

So, we've started a UCEDD and LEND faculty and trainee writing group. We've had I think six of these over the last four years. Some have gone one semester. Some have gone over the summer. So, about 3 to 6 months in any kind of one session where we've identified people. And many of these have been during a LEND training year. And some of them have been in the summer. Where people are interested in disseminating some of their research in a way that not necessarily a peer-reviewed article. Many of the briefs are done concurrently with preparing of peer-reviewed submissions. Some are done after the peer-reviewed journal articles come out. Some of them are more literature review-based recommendations for application of research knowledge.

So, our research briefs are something we're really excited about. The trainees are learning, we're learning what works for different audiences and we're actively working on actually several more of these to come. I wanted to just highlight that.

So, we are actually in the first year of our 5-year grant. We're with a very small cohort that competed last year. Or applied last year and were re-funded. So, we're still getting together our team under the new leadership of Leeann DeWalt who is our UCEDD director. And in this research plan our principal aim, which is provided by the UCEDD grant, is to improve the lives of people with intellectual and developmental disabilities.

For our current focus is to improve access for all. Especially for underserved groups in Wisconsin and then we're increasingly focusing on health equity issues. So, I don't know if that little bell means I mean to stop which I can. Or I could just mention a few challenges and successes and that's my last slide. Do you want me to stop?

>> No, you can continue.

>> Anne Harris: Okay. So, I was just going to say that we are in this new work continually look for new partnerships and collaborations. Including strengthening some of the internal partnerships. Actually, that's been one of our bigger challenges is to really get people who are interested in -- in conducting research talking between the UCEDD, LEND and IDDRC and between the clinics and the preschool and the researchers. Because we are also busy. And we are funded by different groups. Our clinics are funded through hospital contracts and just really finding where those bridges can be built.

And so, we're doing more work in this area. Especially around the issue of autism. Another challenge has been maintaining faculty expertise. And continuing our area -- our known areas of emphasis while developing new ones. Due to a series of retirements and just changing staff we've had some projects come and go. And sometimes somewhat abruptly. I benefited by inheriting the AEIOU study because I had a public health experience, it was a good fit. But, you know, you can't always have people taking on projects and continuing them when other people leave. We've also tried to solve this problem by growing some of our own leaders and having people start maybe as trainees.

And I think a couple of other Centers mentioned this. Who have continued to contribute as faculty or researchers on an ongoing basis. Some of our other successes have been reaching out within the UW system and partnering, for instance, with UW-Milwaukee. With other UCEDDs and LENDs in Illinois and Minnesota. Partnering with our state agencies has been wonderful because they have data and we have research expertise. So, that's been -- been fruitful. And as always, strong teamwork within our UCEDD steering group has really led to new ideas and new ways to approach how to strengthen our research.

And I don't know if we want to say anything, we are filling the research coordinator position. These are the people who contributed to this presentation our website.

>> Luis: Thank you, Anne. Now we have time for questions and answers. If you have

questions, please type into the chat box next to the slides and I will read them aloud for our presenters.

So, Anne, I was wondering, those research briefs are pretty neat. What is the intended audience for those? Are those written in plain language?

>> Anne Harris: Many of them are -- the actual -- what's been fun and challenging about that is they aren't all written for the same audience. So, for instance, I'll just use my own research as an example. I wrote one brief for the plain communities because we had done a survey. And this is the Amish and Mennonite communities. And we wanted to share what we learned.

and actually, well, we have two different pieces. The brief is more for public health agencies. But we also wrote another one for the people in the plain communities. And so, one of the challenges for the writing group has been: Who is your audience? That's like the very first question. Because everybody comes in and says, I've got all of these research results that I want to share. Or did this literature research and I really want to make this accessible, useful information. So, what is your audience? It could be interventionists. It could be public health professionals. It could be the community partners. It could -- like the stakeholders in the research.

We're writing one now for the families of one of our longitudinal studies. So, we really, you know, like what would families want to know after having participated in this research? But generally speaking, it's not the psalm audience as the peer-reviewed journal article. But defining the audience and then figuring out what language is best, you know, suited. So, we do have other folks read these and they go through quite a bit of -- it takes time. We realized we don't usually get one done in one session of a writing group. Usually takes a couple iterations to get it right.

>> Luis: Great. Thanks. So, once again, a reminder to folks, if you have any questions, please feel free to type them into the chat box. So, I have a question for our Vanderbilt presenters. So, you mentioned some guiding principles to guide your research. Have those been formalized and are those public? Are they on your website? Where does that

live?

>> We have not formalized them exactly. We could. And I think maybe we should in some sense. I think these are things that have kind of evolved over the years. But we will take that as a challenge. And thank you for the question.

>> Luis: Sounds good.

>> Elise McMillan: This is Elise. I will talk about that. In one of our UCEDD breakout sessions, we did this with our community advisory council and there was interest. Part of our community advisory council meetings, we intentionally each time invite a faculty researcher to present on one of their projects. And that's been another way I think of integrating both the community advisory council and the research. And also, our community advisory council breaks into work groups. And if researchers do have questions maybe a design of research, we've used that work group time sometimes to inform some of the work by that faculty member.

>> Luis: I did receive a question, and I believe this is for all the presenters. Are they volunteers or become paid staff for research? Funding is such a challenge.

>> So, that's -- this is Anne here. The LEND trainees get their LEND stipend. And for -- at the Waisman Center, we have an all participate in a research project during their LEND training year. So, they're all required to do -- it's like 30 hours. It's not a large commitment overall. But many of them do get hired on to projects. So, some of the ones that I mentioned in slide that shows which disciplines have ended up getting research assistantships with the project. And continued on.

And some of the UCEDDs ended up using the projects for their own dissertation. They don't start out that way. You introduce them to a project, and they have a small commitment as part of their LEND stipend.

>> Luis: Great.

>> Whoops. I can provide information. Or I can provide that as a follow-up. I see that our time may be running short.

>> Luis: I think we have just a little bit of time if you want to elaborate, Elise.

>> Elise McMillan: Sure, our LEND trainer is on the call. She can correct me. But our LEND trainees each receive a stipend and they have projects. But just as Anne said, after that time is up, they may go on to participate in different research projects or other projects within the UCEDD. And depending on the funding for the project and the circumstances, they might also be then paid additionally for that.

>> Luis: Great, thank you, Elise.

>> And there's a similar approach at KU to working with LEND trainees.

>> Luis: Awesome. We are up on time. So, I want to thank everyone for attending this webinar. I want to thank our amazing presenters. This webinar has been recorded and will be archived on the AUCD website. If you want more information about the UCEDD resource center, please feel free to contact us as well. Please take a few moments to complete our survey. Thank you so much, everyone.

>> Thank you.