

This is a test.

Live captioning by Ai-Media.

SPEAKER:

Hello everyone. Welcome to Focusing on Supports to Families: Specific Strategies for Including Family Support in the UCEDD CORE Grants applications. My name is Sarah DeMeo, I am senior manager for you said technical assistance at CAD. Thank you for joining us today. Thank you for your patience as we get started a little slow. Before we begin I would like to mention a few logistical items. I will be turning it over very soon to our speakers and we will try and have an interactive conversation. You can unmute yourself as needed. If you are not speaking, please do keep yourself muted. You can also participate in the chat that is available on your webinar console. This meeting is being recorded and will be available in archive on the AUCD website following this webinar. You can also download the presentation slides that you see on the screen on the event page. Where you got the link to register. There is a short evaluation survey for this webinar. I am going to add that to the chat box in just a moment. We invite you to provide feedback on this webinar whenever you leave, whether that is at the end of the session or if you have to leave in the middle, please do still provide us with your thoughts and suggestions. And now please join me in welcoming our facilitators for today's event, Sheli Reynolds.

SHELI REYNOLDS:

Thank you. Hi everybody. It is good to see some of your faces that I know and some of you I do not know. I am Sheli Reynolds and I am the senior associate Director at the you said in Missouri. I was asked by Mark and Dana to begin facilitating this conversation. Again, we really do want it to be an interactive conversation. For we get started, I want to pass it over to Dana and Mark to tell you a little bit about the Family Support say get. If you would not mind opening up your chat, go ahead and put your name in there, your UCEDD or your state in there and really your role in there. That would be helpful for us as we engage in the different dialogues.

DANA YARBROUGH:

Did you want to run over the agenda first?

SHELI REYNOLDS:

Sorry, yes, really fast! I will spend a few minutes setting the stage for us when we think about family support, family engagement, all this opponent -- components of family that we do in our everyday work, but also as it applies to the Core Grant. Then what we will do is move to some of the Core Grant elements and we will hear from Mark and Dana, and I will share a few examples to, about different

ways that we have incorporated family or family support or family programs within our Core Grant, and that is really where we also want to hear from you. That is an opportunity for you to say oh, this is what we do! That is where the dialogue can really happen. Then we thought we would also open it up. Some people maybe need to know about family organizations, and then we will have Dana and Mark do a closing with us. Sorry about that, Dana. Thank you.

DANA YARBROUGH:

Mark, do you want to grab the slide and I will grab the next one?

MARK SMITH:

Sure. Well, in my career, number one, I come as a professional but in the real world I am the parent of an individual, a child with an intellectual disability and I also am the sibling of a younger sister who has an intellectual disability. So the issues of families has been with me since well before I ever got into this work. And so, when I started with our UCEDD here in Nebraska, the issue of family and supporting families has always been a critical piece for me. And so I joined the special interest group, and I will talk a lot more about what we do at our program, but our SID is really about, you know, the fact that we know, based on our experience, for the majority of us, we could be doing better across the country in terms of how we are supporting families in that really families are the linchpin, in many cases, of ensuring that a person, an individual with an intellectual or developmental disability, has their needs met. We try to engage our entire network, because of its national scope, in terms of supporting ideas, thoughts, projects, initiatives with UCEDD lead and AUCD is that look at family forward to leadership on the part of family forward across the country. And in our individual states. We also look at that same piece within our work with the AUCD network, as far as ensuring that families are part of the core work and values. So it is a big deal.

My sister was born when I was 15, so I have been alive a lot longer as someone who has lived experience with disability then I have not, and, you know, knowing the experiences my parents went through, what my wife and I went through with our son, this will always remain a very, very interest for me and it is a strong interest on the part of AUCD and the network. We are just taking the opportunity to get some ideas out there as we go into a new grant cycle.

DANA YARBROUGH:

I am Dana Yarbrough, I have the fun opportunity of cochairing currently with Mark this Family Support Special Interest Group. I work at the Bergen -- Virginia youth Centre at the variety of roles, I have been there for about 21 years and have a daughter who is in her mid-twenties who has a variety of intellectual and develop mental disabilities and a brother with disabilities, my mother had all time is for 14 years. So I was the bacon or the tofu in a multilayered sandwich. So I know from being a daughter, from being a mother from being a sibling how the caretaking and the supports that are required across the lifespan. So I cannot help but think back when I look at the slide, and you will see this when all this

information is posted, as Sarah said, but we are really super excited that this work of the special interest group has been going on for a while. And it has led to some phenomenal work that is currently happening and some things that have happened in the past. So to learn more about it, please reach out to me or Mark or reach out to Sheli and we will make sure you have our email addresses and we will be glad to talk about any one of these other things that are currently happening or happened in the past. Again, we want to move on a little bit with our agenda for today but we think we bring a lot of value to you all in the work that this FIG is done in helping you plan for your Core Grant application. -- SIG.

SHELI REYNOLDS:

Thanks Dana. Those of you, I don't know who wants to grab it and throw it in the chat, but if you have comments and stuff we want to capture and use other places, you can use them in the chat or you can use this Jamboard. If you have ever used Jamboard before. It is just a fun place. If you open it up on your web browser, you will be able to see the comments in browsers other people are adding to that. We wanted to share that with you. Sarah, Dana, or Mark, grab that and throw it in their full stop bank you.

I want to set the stage a little and share a conversation we have had about -- over the years within the Segal about Family Support and the Core Grant specifically. As you know, every single UCEDD is very different, some are more medically focused, some are more focused on special education. Others are very community and external facing. Both the UCEDD and the LEND all look very different even though we all have the same core function.

The other thing we have always talked about within the SIG is that Family Support is not listed as one of the areas in the DD act when it comes to reporting on needs and doing different things. So there has not been a really great way for us to actually collectively as UCEDD's identify what is all the work we are doing around Family Support and how do we define that work? So there is some added complexity that, too.

And then, because of the structure of each of our UCEDD, some UCEDD actually has the family resource Centre. I know Dana's does, Missouri's does, and other UCEDD's are less focused on more that hands-on support. So there is lots of different opinion about the way that family and family programs and family structures are.

One of the things I want to set the stage with, and I pummelled around with the slide last night, but people talk about family and family support but it is very complex and multilayered in our field. You know, I kind of broken out a couple of different ways is that, first of all, you cannot talk about a person with a disability and either ignore family as part of their support team or ignore the culture and expectations that the family has brought into that person's life, both positive and negative. And so,

there is no way of thinking of person centred thinking or planning without thinking about the family unit.

So one way that people think about the family is that it is always a person in the family is the focus of things. -- The person and the family. That sometimes gets lost when we jumped talking about Family Support. And also, ultimately, talking about that person in the context of their families first and foremost. When we start actually thinking about our research, our information dissemination, our practices, it is about how are we included the families? How are we understanding the family impact on that person? How are we, you know, understanding the culture and the language and the diversity and all of those things around that person as part of that family unit?

The other way, and none of them are as black as widened -- black and white as I am making them sound, but another thing you hear people talk but his family supports. It was 10 or 11 years ago when we actually had the Family Support -- wings conference that we actually said Family Support really means what programs and services are available, what families are eligible for. And that phrase is used in many disciplines, right? You are seeing a lot in social services around foster care and behavioural health and things. And so we wanted to start setting a sort of paradigm shift that says, no we are not just talking about respite programs. We are not just talking about peer support programs. We are actually talking about how do we flip our whole system to really support families across the lifespan and many of their roles? So it is kind of a combination of that family centred thinking as well as the program level thinking.

The reason we wanted to do that is we were finding that researchers and policymakers were starting to really only think about eligibility. Oh, is that out family eligible for that program? When we realized there was a lot more of people that define what family means to them, so it could be those blood related, aunts and uncles, siblings, but it is much more than just eligibility based programs.

The other thing we know about this, and I think this is what LEND is amazing with and a lot of other demonstration projects and initiatives are, is that we have some UCEDD have very specific family positions, meaning they need to come to the table with that limp family experience. And so you are a navigator but you are a family navigator, a peer mentor, a family trainer, family leader. So not only are you may be housed inside those UCEDD and some of those roles, but they also are running programs that have those positions within them and understanding those practices. And so that is where I think LEND is so awesome because to me, LEND starts professionalizing some of these family specific positions that we have but more importantly, it is also starting to recognize ... sitting around an interdisciplinary table, I always say, the disciplines that represent different things, who was actually representing the discipline of family, right? So that is another component of it. It is like no, no, no, they are not just there because they are a family member. They are there because they are representing the needs of the family and the family unit. And that kind of thing.

The other thing that you really start seeing as you see levels of engaging family. So how are we engaging families and the needs assessment process, ongoing projects? So there's family advisory councils, family feedback surveys. There is also a way for families whose family members receiving service to also influence, advocate, and engage with policy change in practice level change.

I put this last one on thereto because, you know, sometimes we are not here because I am a sibling. I am here because I am a researcher and a trainer and I am interested in this field, and I so happen to also have that lived experience. And so sometimes we are very intentional about our positions, like up on that middle column. And sometimes it is about how our UCEDD just being inclusive of self advocates in families as all of the positions? As directors, evaluators, trainers, as researchers. And they do not always have to have that caveat in front of it. I am a self advocate researcher, a family researcher, right? So I want to kind of put that on the table.

The other thing that over the last 10 years that we are doing and pushing for, inside both UCEDD and in the field, is getting people to stop just thinking about the traditional family structure of mom and dad. Of thinking about that there are siblings involved, there is divorced parents involved, whether you are doing this because you are hosting training or whether you are doing this because you are looking at research, do we understand the impact of divorced families? Do we understand intergenerational relationships? Our grandparents living at home? Is there the whole sandwich generation in the same home succumbing one another? -- Supporting one another? Are we looking at different types of diversity? Same-sex partners? Are we looking at how the person to find their family? Maybe they do find it in terms of nonblood related. Maybe it is the next-door neighbour who is family like to them. So when we start digging about who is in someone support circle and who do they consider in their closest circle, as they define their family, what is that family structure?

We also cannot ignore the family member types. And we are starting to see, you know, 8 to 10 years ago with the sort of national sibling leadership network, siblings started to really kind of rise, but fathers, extended families, grandparents. And we cannot ignore the parent with a disability. So when we are think about Family Support, are we considering that parent who is parenting with a disability? Raising children maybe with or without disabilities? And so, you know, it is kind of understanding is different roles.

Understanding different cultures, diversity, beliefs, and language. Whether we are doing this both by looking at our needs assessment or we are even thinking about how we provide information. Is it information that is addressing the many cultures in our state? Are we researching and understanding the differences between the support needs and the different types of ways of implementing our different evidence-based practices to different cultures?

We also, thinking about the different geographics. You know, families that are growing up in rural communities versus urban communities versus suburban communities. That has an element of understanding beliefs about disability, access to services and so how are we understanding supporting those families in this different environment? Closely linked to that, though, is also the socioeconomic status. You know, it is interesting, when we often think about Medicaid, we push Medicaid all the time and a lot of times we start really looking at, there is a big need to really address the needs of families in this lower socioeconomic and poverty level, but we also cannot forget that families that are middle-class do not have access to Medicaid. So they are reliant on their insurance companies and so when we start looking -- working on policy change, we cannot always just think about those families that are currently getting Medicaid, maybe eventually their child becomes eligible for Medicaid and community services. But there are different needs based on your socioeconomic status. That have to be considered.

We also know the different life stages. And so, you know, families who are aging and worrying about what is going to happen when I am gone? The family who just received a new diagnosis, how are we understanding supporting them in whatever sort of lifestage that they are in based either on age or life events?

The other thing I think is really fascinating when we are thinking about family across all of our research and practices and policy changes, I was thinking about the generational differences. You know, the older families that fought so hard to keep their children out of the service system or out of institutions to the newer generation that is growing up with more inclusion but not necessarily, there are still a bunch of barriers, right? So what are the generational differences and expectations? A big one that really came around for the national community of practices, there is an assumption, when we are doing research you cannot assume that just because he ran Medicaid data, you know everybody who went to the DD system. Because quite frankly, we know only one in four people with develop mental disabilities are receiving Medicaid waiver services. So that pushes our researchers to have to think very, very different leave. Every member doing a big project in Pennsylvania and they said what we have access to the entire Medicare database, we can run whatever you want. And I said, "well how do you know if they are in an (Indiscernible) waiver?" And they were like, why would we need to know that? So there is even an understanding of the data that we are looking at. If they are getting services or if they are not getting services. We can also be looking out one of their needs? Their wants and desires? Based on the services that they want, or maybe they don't want them. Why don't they want them?

So we are thinking about the demographic around the concept of family, there are many many different aspects. Of course, I probably did not cover all of them, but these are the big ones that we are constantly pushing ourselves when we are working on policy and practice in researching. -- Research change. So I just want to set the stage, because sometimes when we sit down, I think the thing we are

all challenged that is probably most everybody on this call is pretty familiar with what I went over but you work inside of UCEDD, so you work around a bunch of researchers that do not think about all of these dynamics, or think about all of these components. Or maybe you work with the UCEDD Director who is only focused on, you know, some sort of family support service and so some of this is about us as a Segal, as peers, about how do we even sell this inside our own organizations? How do we even convince them during the Core Grant that these are some areas that they should be considering? And quite friendly, every area that considers a person should not them nor the family component of that. So there should be nothing written in the Core Grant that leave some element of family out. And so maybe they are not thinking they are doing Family Support, because it does not have a specific program or grant listed under it, but we need them to recognize that families need to be everywhere within that grant.

So that is just a really, really quick overview. But I want to take, I will come down off the screen and open it up now. I would like for Mark and Dana, whoever wants to go first, to ... everyone is structured a little differently, so tell us a bit about the culture inside your organization as it relates to family and the little LEND and family programs and that kind of stuff, just to give everyone an overview.

MARK SMITH:

I can start if you want. My relationship with our UCEDD, the Meyer Institute in Nebraska, is a unique one. I have been here about 20 years and when I started, I was the only person that was actually supported by the Core Grant specifically around family. So it was a department of one. And, you know, many of the things we talked about were things that I began espousing to, in particular to the trainees that were coming through our program in terms of the value piece. That, to me, is exceptionally critical. If we lose our core values around families as the experts on their family member with a disability, you have kind of gone through quite a bit, then we really are nowhere. And I also, you know, have the belief that having lived experience adds to what you bring to the table as a professional, because, you know, I have a background in psychology and have worked for years in the field. But coming here was a real change in that really, there was not a focus on family. There was not a focus on the lived experience of people with disabilities at all. And so the first thing that I did was put my name up on our website and said if you need information, feel free to call. And I got a few phone calls. (Laughs) A few phone calls. One of the things I found for families, especially from a value standpoint, is information a significant currency. In that semi families -- so many families are in different places. They may be thereof long -- but very far along in very savvy or they might be just starting out, and everything in between. We are talking about systems that are not always easy navigable. They were not for me, and I had been working in them for over 15 years. So I really try to push that idea of number one, we are going to be a resource to individuals and families on disability issues, services, and supports and that that was going to be something that we would kind of start to voice in the training work that we were doing.

And now we have about 30 people here. And about four fifths of them are family members. That was not all me, but at least, you know, that has been over time as we have been able to leverage our way into different projects and activities, we have hired professionals and they just happened to be family members. We did not have to ... we did not make that a requirement. But we value that lived experience component. So if you come in with resources, experience, background, training and you also happen to be a parent or a sibling or in some way have a lived experience piece, if you are a person with a disability yourself, we see that is adding to that individual. And a lot of that has not been related to how we have put our Core Grant together. A lot of that has been our opportunity through project with our department of education, with our Health and Human Services, and program. We really try to build ourselves as a resource to not only individuals and families but the networks of services and supports. And we have had some success with that.

So we have really kind of put family upfront and at this point in time, we are trying to keep that going in terms of ensuring that people with disabilities voices are also heard. Those are two things we are looking at within our discussions around our Core Grant. We have a lot of projects that involve families. We really need to look at our Core Grant in terms of how it leverages our work towards the supports of families, you know, given the complexities. With the family, you know. The thing that we have done over time is just if you say you are a family, you are a family (Laughs). And tried out to put ... you know, it is too easy to get caught in terms of background, culture, socioeconomic status, parents with disabilities, you know, we just decided not to exclude anybody. Because that way, we did not put our values on other people's life experiences. We just said your life experience is important and knowing that, for example, in our state only about one fifth of individuals with disabilities are actually receiving services in our state. That means four fifths are not. And who are supporting them? Family. So we are really trying to up our game at supporting families, because we know that that will have a positive impact on people with disabilities.

I will talk a little bit more of some of the projects we have, but that is just a quick introduction.

SHELI REYNOLDS:

Thanks for that history Mark. Mark, you have the UCEDD and the LEND there, so that kind of structure, that's important for people to know. Dana, do you want to talk about your structure?

DANA YARBROUGH:

Sure, we also in Virginia housed the LEND and our UCEDD, we have just about shy of 40% of our staff are family members or people would lived experience. Some of those people were intentionally, it was in the jobs caption that it was a preferred or required experience, you had to have lived experience. So some of our jobs are written very much that that is a requirement, sometimes people end up in the field as Sheli was saying earlier, we know people who end up working in the field if we have a family member, a lot of us go through college and end up in careers related to disability. So we

have kind of a mixture of people who are in specific family roles of those who are family there was a lot of other roles.

We had our UCEDD have a, out of our 40 projects, we have taken some of them because they are intentionally finding direct support to families or a lot of intensive training and technical assistance to a broad variety of providers who support zero all the way to the grade, -- grade, we have professional development on equitable and compassionate engagement with families. So we have moved a lot of that work under one large centre. Our Center for Family Involvement have a little over \$1.5 million, so that was one new -- way we tried to structure. What we do not want to do is become a silo and one way we've tried to do a void that is that through our Core Grant, there is money similar to what Mark was saying but it is a little different in our UCEDD. We have a family audience leader, so it could be a 20% effort, depending on which year we are at the Core Grant. We have ever dedicated for someone to serve in that audience row, do serve on our leadership team with the Executive Director, to work on our development and grant writing team, to make sure the family to boys is infused in policies, practices, new projects.

I would just add that our LEND program has has I think at least since 2007 or eight, they started a family discipline. They had family faculty and staff. We have family mentorship stop. And we have often have our clinic coordinator is a family member. So we have really tried to have our LEND program also embodied this idea of families being in the leadership roles in those programs.

SHELI REYNOLDS:

Thank you Dana for sharing that. To give you a quick overview, in Missouri, we are sort of a hybrid of both what Mark and Dana were talking about. We do have a portfolio of a lot of projects related to Family Support. So we have elevated equal to all other priority areas of the DD act. So we actually really focus on ... we do not call it a centre, but we do have our statewide family health information Centre and it has additional funding from our DD Council and our state DD agency to do that direct support to families around peer support and information dissemination. So that is probably as close to direct services that we actually get inside our UCEDD.

The other components of our UCEDD is that where it kind of crosses over, we do do a lot of research and a lot of policy and practice change with life course and all of our sort of strategic family support initiatives. So we have a full family support team working on all of those projects related to that. But we do it completely connected to our individual advocacy teams. So we never disconnect those two from the persons and their families point of view. Those projects are always working pretty reciprocal and in conjunction with one another.

So we are partnered with our LEND who is at a sister campus in Columbia, Missouri. And so we do a lot with them. We present to them and so we bring some of the family component to their additional

family disciplines component. So that is a little bit about our structure. I would like to open it up to the group. Does anybody have any questions? Are as these similar to the way you are structure is? You know, are these things you are wanting to put in place or try to figure out how to, you know, design? You have them, you don't have them? I want to open it up to the group?

MARK SMITH:

I don't think they were ready to talk! (Laughs)

SHELI REYNOLDS:

I can see some of the names on here, and they are talkers! I am not believing they are not ready to talk! (Laughs)

MARK SMITH:

I agree with you!

SPEAKER:

I will add, I have put some of the comments that have been suggested by Mark and Dana and Sheli as ideas on the Jamboard. I also added a few resources specifically for your statewide needs assessment part of the Core Grant application from the URC resources on there. Specifically, I added the child trends database and the kids Count data centre both have good data points that you can use to identify the needs of families in your state, whether that is, you know, homelessness metrics, immigrant language, there are a whole bunch of different categories you can sort in both of those data centres that can be good for informing the needs assessment portion of your Core Grant.

SHELI REYNOLDS:

That is great, Sarah. So, if you have anything, stop us at any point, but I also think that the Core Grant writing is always a really great opportunity to insert in areas where you wish there were things happening inside your UCEDD, right? So it's like a chance for ensuring that it is coming up in your needs assessments, identifying it as key priorities or outcome areas. And so just, Mark and Dana, do you want to start us off quickly of how are you involving this sort of family boys, or the family perspective in the needs assessment process? In addition to the data?

MARK SMITH:

For us, it is a matter of reaching out to and collaborating with other entities in our state. Not only our federal partners, but family organizations as they existed. We really try and do a lot of construction based measurement, so we are working through other folks to make -- get input on what they see as being the current issues and needs. We are fortunate to have a pretty strong program evaluation group here. So we partner with them to get information out and one of the things we deal with two in Nebraska, and this is true, in many states, is we have very, very rural areas. And then we have fairly

urban areas. So how do we get to the individuals and folks, and that is by inviting folks in. In one of the things that we have done in terms of our project is they are all kind of hybridized in terms of what we do within our larger communities versus what we do in terms of our more rural or frontier communities. We have a couple of frontier counties. I will not go into that, that is just a lot more cows than people!

We also look at, like, we work with our federal partners in terms of the perspectives they have on what is going on in the state. So we try and pull from many voices but we particularly want to hear from the people at our receiving services. Who are eligible to receive services. To ensure that the directions that we are proceeding in are validated in that way. That what we do is having the intended outcome versus just plowing ahead. And I think that is what is really valuable about reaching out to organizations like the family to family or Easter Seals, I could go through a very long list, we try to maintain very close relationships because one of the things that they provide for us is that additional set of perspectives of the people with disabilities, their families, and other professionals that they work with as we work through together for the assessment.

DANA YARBROUGH:

I will just throw out that one of the things we have begun to do about a year ago, we went back and did a look back of all five, the last five years, of all the research we had done about families. We either did focus groups, listening sessions, online surveys. And we pulled it together and even our family to family data, and stuff that our family discipline trainees had said, and some of it worked well and some of it did not match so well. There was a lot of beaming and chunking and looking. Out of that, we were able to come up with a framework of what it takes to support families really well in Virginia and I think that is something that now we can use to put into our Core Grant as something of -- part of a framework for moving forward with maybe some of how we read our goals and programs so that is one way for that particular section.

We looked internally and externally, I would just add that there is a lot of research happening right now around COBIT impact -- COVID impact and I think UCEDD would find people are just beginning to find -- start publicly that information that has been collected over the last 12 or 14 month. As we see things, we will make sure AUCD list serves are posting those that we will try to have a space for that sake to try and keep track of some of those as well when we see those reports.

SHELI REYNOLDS:

Thank you Mark and Dana. I would add to this, in Missouri, in some ways sometimes we go to write grants, especially the Core Grant, it is hard to always pinpoint exactly how we do it, because it is the only way we know how to do business, right? So we have an ongoing stakeholders group that is including self advocates and families for 20 years. So it is almost we have all these rolling activities, so much like Dana, it's like how do we go and collect the stuff that we have been doing the last couple years? We do not always have to go and do a new thing, just because it is time to read the Core

Grant. It is also about building a number of years states have a national community of practice is going on in your state. So are you involved in that? Are you getting information from those bigger initiatives? Looking at sort of the Family Support concept.

I also think it is a nice reminder to also, you know, when we are hosting, if your organization is hosting focus groups were surveys, how are you getting it out to the complex group of people that we listed there? Those that are not getting services. Are you working with early childhood? A Special Education? Because sometimes it feels like the same focus group participants in the same survey participants are constantly the same. So really pushing ourselves to find different ways to get into some of the pocket through some of the entities as well.

So I would like to open that up to others that are on this call. You guys have additional ideals and strategies on how your engaging families in the needs assessment part of it?

SPEAKER:

This is Stephanie Coleman. In Kansas, next door! I think about what Mark said about the frontier. We have a few of those frontier counties to, but our parent training information Centre, myself, and our title V are going to be working on a project here later this year to do some mixed in person and virtual trainings for families across the state. Because, you know, Shelley, we are both in Kansas City and it is great, we both have everything we need right here, but I get so frustrated because we cannot reach those families out of the rural and fronting areas that need so much more. So, how do we connect with them? How do we first teach them to lead and advocate, but then also kind of put in me little ideas in their head that they could become a BC BA. They could provide ABA services in their area. Or residential lowercase management or whatever it is. And then also, in hope of what I would like to see, is like siblings. Now siblings, you know, their parents have interacted with people from the University in clinical areas, right? So do they start getting interested and want to come to KU or Nebraska or wherever and get that and then bring those skills back to their small town? That is what I want to try and find and we are working on a project together on that.

SHELI REYNOLDS:

Thanks Stephanie, that is awesome. (Unknown Name), I see your head raise.

SPEAKER:

Yeah, and California ... California always does things the California way, and we have enough people and enough different programs that it can be in either a very good thing or a very confusing thing. But I think some of the ways that we are successful, I mean, we have people that we have easy access to. You know, through our mailing list and all of that. But I think we also depend on once removed relationships. And so, you know, for example, we have 47 separate family resource centres throughout California. Which can be very confusing because you cannot just go to one family resource Centre and

have it represent all of California. But on the flipside, we have the luxury of having family resource centres that are embedded in their communities and know their communities really, really well. And so while we may not have the ability to reach into every one of those communities, we have the ability to hear from folks who know that community really well and so, you know, some of the ways that we gather information is not directly from families that are hard to reach but for those that are actually reaching some of those hard-to-reach families.

SHELI REYNOLDS:

That is helpful, Fran. And it is amazing how fast our time goes, right? So I want to kind of also direct a question. We know there will be a couple of things coming out when we think when the Core Grant drops. It will obviously be a lot related to the diversity, equity, and inclusion concept. We like to add the word belonging onto that because it is one thing to be at the table but it is another thing to really be a part of stuff. But I also, there is a big push, which is really great and I think we have been saying it for years, that we call it family-friendly information but even pushing this further to plain language. Easy readers. So as we are thinking about not only how are we reaching families but how are we reaching them in a way that is in their language, words within their culture, but even, you know, pushing our efforts around information dissemination whether it is research translation. Whether it is the rate we host our training workshops. I think that if you think about dissemination, both in specific projects but then also in your overall dissemination plans, I think it is important to be thinking about aspects related to that. Either any sort of ideas or thoughts related to that because that is going to be the things we are all addressing?

DANA YARBROUGH:

This is Dana. I just wanted to, a couple things we have been doing, one we hired some parents and some use -- used to develop tick-tock or Instagram videos, things that we contract with them and they get paid for whatever that particular topic is, and maybe translating research. They meet with researchers and figure out how the best ways to translate that to families is. And then they do videos. We have had a lot of success with using social media and having parents coming just as contractors to do some of that work. And then the other what is we've always done a lot of localization with what where we take information that is Artie written. We take it to a community, a cultural or liquid sickly diverse community, we asked them to tell us what this means in their leg. How would they say this to another family? And then we asked them now that you have said that, how do we make that into a format that is preferred? So it listed vastly different from what it started with and it is a long process. It can take six months sometimes to do translation. It is not quick. Sometimes it can happen a month but it takes money to make sure you are paying people to come together.

MARK SMITH:

For us, a lot of our work around COBIT in families, which is a pretty critical issue, has been going to the community, getting individuals from that community to take the information back and share it

versus us taking into that community. In other words, when they look up, they see a face just like there's and we support them in terms of linguistics, in terms of culture, in terms of messaging and all of those pieces to ensure that, you know, along lines of family and plain language, which for me is just an issue of accessibility for everyone. But we are sensitive to how best to meet them where they are. I wanted to say one other thing too, one of the things that we and I have pushed on for quite a few years is that we infuse the family component and the person with a disability component into activities in all the core areas. For a long time, you would never hear about families or individuals with disabilities working on a research project. And we are trying to turn that on its ear. I know, for example, that cola has taken that up as an issue. In the fact of the matter is once you have advised enough pre-doctoral trainees on the importance of the family perspective, Ed the person with a disability perspective, when they come back to your institute and start running departments, they may write grants that have families in them. And so, when we look at community-based services and supports, or information dissemination, those are kind of the first place at the start. But we do not want to stop there. And we do not want to stop in this next round in terms of the Core Grant as far as ensuring that there is a strong family perspective infused into our research and evaluation in our education and training components.

SHELI REYNOLDS:

Thanks Mark. I put two links in there. I do not know if you guys ever go to the Georgetown resources from their national Centre. But they have an incredible paper related to disparities. Because accesses a lot of the stuff you are talking about. Access to information. Access to research. Access to services and supports. And they have a really great way of helping you think through that. They also have resources on there that I think they did with AUCD on really how to make stuff culturally and linguistically appropriate. So I recommend that. The other thing that I would encourage you to do, because we are running late on time, is if, you know, so often UCEDD are not connected to the family support organization grassroots network. So where are those? In our community, we have a black family group. We have a transition group. And so I think that it is important that the UCEDD figure out a way to support these local grassroots based programs and initiatives and groups, because they are all creating their own websites and their own training and their own ... they all need help in this area to make sure one, that it is aligned with federal policies and practices, but how are we building the capacities of that infrastructure of this grassroots Family Support movements? The other groups that are always usually at the table are your big entities. Your ARC are usually there, some of your other big things that are also sometimes advocacy and sometimes provider. But do not forget the entities, those true local entities. One how are they at your table during their needs assessment? But to, how are you helping them in some of your project activities and programs? Any other sort of closing word, Dane and Mark? Again, we are available, if you want to call us individually or email us if you are getting stuck on something we talked about, where you want to brainstorm with us, you can do that. But I will pass it over probably to you, Dana for closing remarks.

DANA YARBROUGH:

If you go to the AUCD website and just Google AUCD Family Support, Sega, it will take you right to the page. It will be and maybe some of the materials we put up after today. If you are not part of our SIG and you want to come out to our violently meeting, there is a place where you can sign up on some of the pages so please do so. We are hoping that if you will kind of take a moment to go into that Jamboard and go through a couple of the pages, if you have an idea to share or a question, are SIG is going to be meeting in February and we would love to be able to make a product of what we have learned from you also we can send that out to the network with some fabulous ideas.

SHELI REYNOLDS:

Mark, did you want to say something?

MARK SMITH:

I was just going to say one of our priorities been over the last several years is to do community training, we are taking the training for the community and the goal is to build local grassroots. And then we are automatically connected because we are spending days with folks and it is more virtual now, but I really like that point, Sheli, because that is exactly our focus which is we are trying to get out to the far western parts of our state and really work with individuals and families and get them connected to each other and through that training, they are connected to us and then we are getting data and we were able to sub -- disseminate information and resources and that just has really been a fruit roll approach.

SHELI REYNOLDS:

Thanks Mark. Of course I could just keep adding things on but two other things to consider is your state agencies are trying to figure out how to put into their policies and into their waivers and funding specifically how to fund Family Support. Right now is the time to make sure that you are doing that, if you're providing technical assistance to your state agencies on policy change. The other big area, and I think Fran brought this up to, is looking to UCEDD to trained professionals about the family unit and the family discipline. Whether you are working with support coordinators, early childhood, home visiting. How are we bringing that component to the table with other professional development disciplines. So those are two big areas that there is a lot of discussion on currently. Sorry Sarah, I know that you are popping on.

SPEAKER:

Yep, I was just going to say, I put the link to the event survey in the chat box. And I also wanted to mention that Monday is my last day with AUCD. I have accepted a position with the amputee coalition, another ACL funded TA Centre. And so I am going to be doing, I will be the director of peer support programs with them. I have tremendously enjoyed my time over the last six years working with this group. And with you phenomenal people, this is my last webinar with AUCD and it is so fitting because

this is really the heart of why I do what I do. And I'm going to miss you all quite a lot! We are still determining who will be staffing the Family Support SIG and I will send the Norton to the listserv on Monday. When we have sorted that all out. So I just wanted to take one minute to say that at the end of our time together today.

SHELI REYNOLDS:

Congratulations Sarah, we appreciate your support.

DANA YARBROUGH:

And we wish this was another 30 minutes. There is so much to share. But again when the Core Grant comes out you know how to get a hold of me, Sheli, and Mark if you want to talk through anything when you see the RFP. Because I do not think it is out yet.

SHELI REYNOLDS:

Yes, thank you for coming. And participating. We hope that this was helpful.

MARK SMITH:

Thank you all.

DANA YARBROUGH:

Thanks, Sheli.

SHELI REYNOLDS:

Think you guys. Thinks Sheila -- Sarah.

(End meeting)