

REALTIME FILE

AUCD-Families: What They are Saying, and how UCEDDs and LENDs can help  
Tuesday, May 19, 2020  
3:00 p.m. – 4:28 p.m. EDT

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>> I'd like to address a few logistical details, because of the number of participants your audio will be muted.

You may send a Chattanooga to the whole audience or presenters only.

This entire webinar is being recorded and will be available following the event.

There will be a short evaluation survey at the close of the webinar.

We invite you to provide feedback on the webinar and also to provide suggestions for future topics.

I will now pass the mic over to early childhood special interest group chair Mary Beth. Mary Beth?

>> Mary Beth: I want to welcome everybody for this webinar.

As most of you who know who are part of the early childhood we have been doing more frequent webinars because of COVID-19 and how everybody is trying to cope but most importantly serve the constituencies of families of young children with disabilities. However we have the opportunity to serve people with disabilities.

Our first webinar was to hear the status of part C, programs across the country and last weeks for those who joined that was the Executive Director of the Infant Toddler Association, last week we had the Director of the National Association of Special Education State Directors.

They both gave us their view of what is happening currently and how UCEDDs and LENDs can help.

What is most importantly is how we can help the families who we serve.

We have been very active as all of you at UCEDDs and LENDs how best to help families and as a result we have a couple pieces of data we will share before I turn it over to the University of Connecticut who is Molly Cole, Darla Gundler and Ann and Rud Turnbull who need no introduction.

We are thrilled they have been consultants to our programs.

They are our experts beings they will react to data we will present to you and we will

hear data from them also.

I would like to also acknowledge the university team, the early childhood team has been right on top of family needs and we have asked them to share a little bit about their data before we share some of the University of Connecticut data.

So, Natalie, we are going to have Ruby start off, Ruby Natale and she will share from her colleagues the data they have been busy collecting.

>> Ruby, I need the host to allow me to share my screen.

I'm from the University of Miami.

We put together a survey call the risk and resiliency in response to the COVID-19 pandemic but this was more than a survey, we developed the survey to then find ways to intervene with the families in our community who are affected by the pandemic.

And, so, the results of the survey allowed us to form a triage system to then connect families with the services that they needed.

So just a little bit of a background on our sample we collected the survey for a four week period from the beginning -- end of March I should say until the he end of April and we received 230 responses.

So not as large as UCONN but we were happy to see we had 81 zip codes throughout our area and 27 zip codes in the county so we were pleased to see that we reached more than 75% of the county through our survey.

Also being in my immediate county we are very ethnically diverse community and, so, our responses, we had 56% identifying as Hispanics, 17% African-American, 20% white, 14% Black and 4% other.

The mean age of care givers was 34 years.

The programs we surveyed 41% of the responses came from programs that served children with mild to moderate surveys and 3% from mild delay, 27% of the surveys were completed in Spanish, 2% in Haitian Creole.

The results are pretty bleak, we asked families for a variety of information regarding how urgent they needed services, the type of services they thought they needed.

How disruptive COVID was to their lives.

The issues that they are experiencing, their feelings of confidence related to managing every day stressors and what were the causes of the stressors.

26% reported they were in urgent need of service.

The types of services most needed were online workshops for parents and activities for children to do.

Unfortunately 23% of the population said that on a scale from 1 to 10 COVID was a 10 out of 10 disruption in their life.

The types of issues that families reported were things that we expected, not sleeping well, feeling anxious which I think most of us can relate to but we were just surprised by the percent of those experiencing these issues with 73% experiencing anxiety, 41% sadness or depression, anger, feelings of confidence, one thing that is important to me is the issue surrounding food insecurity and 28% responded that they were not confident in accessing well balanced meals for their families and 37% not being able to manage their child's behaviors.

Again, the main cause of stress which was heartbreaking was not enough money for basic care like clothing, housing, food and healthcare.

And 47% were experiencing difficulties keeping a job.

And for me I think the most impactful response that we saw was that 60% of families of children with mild delays we were serving were not accessing therapeutic interventions once the model was switched from in person to virtual services.

We had a mechanism in place no longer we could do into homes to provide therapy, we were still able to offer services in a virtual format but 60% of those families did not take advantage of that.

And, so, there is a host of reasons, mainly due to being overwhelmed with their current situation which, as you can see from the slide above, we all can relate to that, but it's definitely an issue and something to pose to the group and I know that we have families on for further discussion.

>> Mary Beth: Thank you, Ruby, thank you for your team.

I have to tell you how impressed I have been working with this team and in very little time we have met and find kindred spirits at the other end of the country is fun and I admire the amount of data they have been collecting and their intention of getting a racially diverse group and group that is most needy.

Darla, are you going to do the next slide or do I do it?

>> DARLA GUNDLER: I think you were going to do this one.

>> Mary Beth: Let me do this, then I have to share screen, Anna?

Thank you.

So what I'm going to share is?

Data we collected at the university with my team.

Let me get into the slide show so we can see.

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There we go.

With the team here that really also came from the public health sciences department, one of the issues that we found in UCEDDs is they have a great finger on the pulse since COVID-19 started.

There was a survey that went out about the knowledge, attitudes and behaviors, we adapted it to parents of children with disabilities.

My colleague and I have just started to dig into the data.

It's is much more broad based than the Miami data.

We were lucky getting a national survey because we went and asked for distribution and the majority is from Connecticut, this is not the full sample, the full sample is over a thousand.

What we have pulled out here are kids, families of children identified as having a developmental disability or special healthcare need and as you can see we were very lucky that we got a diversity across states.

The age is somewhat skewed in that we have a mean age, most of our folks responded were middle age or so but we have as you can see a wide range.

We got a number of families who said they have older children living at home, could they answer?

Primarily female, primarily white and primarily highly educated, we have a skewed sample and we know it but they told us a lot.

81% married with a partner.

It skewed to middle age, small numbers on either side but we will dig deeper a little into EI.

We asked specifically, for those who saw the survey, it's a lot longer, we picked out what was most important to react to.

We asked what are your two most important need, concrete needs for your family right now and basically through going through these open ended questions we were able to theme them and number 1 was special education, access to education, EI, what types of supports and trying to figure out what their children should be getting, those children being mainly on IEPs.

The second were financial, money, finances, bills, income, the real issues that we're all facing right now.

Child care respite, as you see the skew of our data, most of these folks are four year degrees, most are working so they need to figure out how to keep their children occupied.

Mental health stress release and physical health.

This is going on, this shows parents have some very concrete needs right now.

Most importantly when we asked about current anxiety level, if you look here, it's about 75% of families currently had a high to somewhat high to very high anxiety level which is, again, a day-to-day generalized anxiety we all can relate to as did the Miami families.

Lastly we pulled out some of the things families told us about their family situation.

We had families both parents are laid off.

Here is a need they had, ensuring that our son gets the supports he needs during this time.

I am worried that he will regress in learning and behaviors, he's been doing well and I don't want him to regress.

Another one, understanding what IEP services my son should be receiving and how he should receive them.

And lastly trying to juggle digital learnings with disabilities and working full-time.

So I think as you look at this look at our data and look at the data from Miami, families are being open and sincere in what they need now.

I am now going to turn it over to Darla Gundler and Molly Cole who will share one more piece of information, it will be the piece of information before the panel of experts will react to it.

Darla, do you want me to keep going with the slides?

>> DARLA GUNDLER: I do.

We have hosted family cohorts, one and two calmly cohort for the past 25 years, this is 25 states, these individuals are family leaders, emerging family leaders and we engage with them on a monthly basis on -- in a community of practice and in those community of practices we have had the opportunity to get to know them well.

They engage for one year and, so, this just happens to be the middle of cohort 2's year.

On the next slide you will see these representative families, they have a lot of affiliations within their states, they are members of parents centers, engaged with the parent centers, belong to state organizations, may be a member of the council, they

are partners in policy making, they are trained parent advocates and some are LEND graduates.

So, as you will see, these are family leaders that have actually gone above and beyond and our goal to work with them is to engage them in their comprehensive system within their state and we do this by having them focus on one area of the ECPC.

All have children that are or have been enrolled in early intervention.

Molly and I asked them in the last two months, we have been on the call with them in March just before everything closed down.

Then in April, early in April we took their temperature to see where they were, so, Molly, do you want to start with some of the things we've heard from them?

>> Mary Beth: Molly, we can't hear you.

>> MOLLY COLE: So, when we took the first call after quarantine and everybody came on the call and we were really impressed actually that parents came on the call because we knew there was a lot going on in their lives and we asked them what, you know, what do you need from us?

What can we do for you?

And they basically said we are really overwhelmed, we are really stressed, we are really exhausted.

We have everything going on, we are trying to work, we are trying to be teachers, we are trying to manage our households and keep ourselves afloat and that was their big, big concern was that they just wanted a space to be able to address some of that.

They are exhausted and they have so much on their plates that it really is mind boggling to listen to them at times in terms of what their days are like.

>> DARLA GUNDLER: So we had a survey before the first call and we asked them to rate what their biggest concerns was and the first was health and safety of their entire family and that actually came out loud and clear, comes out loud and clear on every one of the calls.

And the biggest concern is when we asked them not for their own family but families within their state is the disparity and, you know, where things are and we've actually had a number of our members of the cohort have actually lost family members due to COVID-19 and trying to explain that to their children, it's been really heart wrenching to be on the calls, this was an opportunity and they took the time to get on the calls, this was important to Molly and I, we are energized from them because they just needed to be with other families.

>> MOLLY COLE: The next thing they talked about is they really needed accurate and realtime information and guidance and particularly if you think back to the early days of our quarantine there was a lot that was floating around in resources and not all of it was accurate and even today not all of it is accurate and, so, they were a bit frustrated. They were very frustrated about not having adequate guidance in their role as educators.

Figuring out how to modify work being sent home without any support or guidance, one of our moms said she has three children, they came home with three different sets of applications and programs, they are all trying to access technology at the same time, it is really, really tough.

And they are not getting a lot of support in how to manage all of that, how to manage

the various programs their kids have to use.

One was sent home with a pile of worksheets.

She said we have never done worksheets before, now I have to figure out how to do worksheets.

It was very difficult.

>> DARLA GUNDLER: I think the other thing she said is this is general education class work for my student that has an IEP and is in special education so they are expecting the families to figure out how to modify the work into special education so that was very interesting.

But then one family shared she has been able to step back and see the child and family's strengths in addition to the challenges but what they have been able to see is how amazing her son was doing and it didn't reflect that on the IEP and didn't reflect it from what the children were telling the family about so it was really an opportunity for mom and dad to say we will revisit the IEP when we go back because he can do more than you are communicating to us.

But then the challenges of the behaviors at home and some families are saying their children are regressing but their behaviors are coming out because we are human creatures and not used to being locked up in a house, not able to go out and be social, we are social beings and we have encouraged our friends through inclusion to be social beings.

You can't be social right now so we are telling them everything we told you before you, you are going to stay home now, that has been a challenge and they have seen a lot of challenges in behaviors and kids acting out.

But to be honest think there are a lot of adults too acting out because this isn't normal for us.

>> MOLLY COLE: And then the last thing they identified that they really just want space to be a family.

You know, when you have a parent with a child with disability you get comp boarded with a lot of things and sometimes you just want to be a family, step away from all that, don't want to be the teacher.

We see the lovely ads on the TV the family is sitting around doing family things.

Well, for families who have space, that's great.

What you do need to understand is when you are a family cramped into a small apartment, maybe you don't have a yard or maybe you are not in a safe neighborhood, maybe it's not anything that you can do, but it's really hard to just find the space to be a family, let alone be a family and then be a recreation director and then be a teacher and then be a therapist and try to keep everyone on an even keel with their behavior at the same time.

What they really talk about is they just need a break from all of that, sometimes they need permission to step away from having to do all the things that we often ask them to do.

We were particularly proud of one family who informed us on the last call that she had made the decision that she was not going to take summer extended year program because she really felt that they needed a breather and they needed a chance to just be a family and that it had been too stressful to try to implement all of that.

So I think what we look for here is a way to help families strike a balance and they were very clear about what they needed to do that.

>> DARLA GUNDLER: So now we ask the question what are some of the things that UCEDDs and LENDs can do because it can't be business as usual moving forward. So we came up with the top 10 list of things that we think that UCEDDs or LENDs can do moving forward and the first one is to position the UCEDD to be a resource for families to supports each other.

When families say I don't know where to go in my state the first thing should be where is your UCEDD, do you even know what an UCEDD is, if you are a family with a child with disability you should, if not we need to do a better job to let you know that but are you working with your parent center and I think those are things we need to be encouraging is more of that collaboration.

Maybe one of those things is parent to parent mentoring.

>> MOLLY COLE: The second thing that we thought of is that the UCEDDs and LENDs could act as a clearing house for resources and referrals that could help families access food because we hear a lot about food security, housing security and safety and that really involves linkage into communities and community building and recognizing the various levels of support that should be available to every family. So families, when they express to us that they are having difficulties with food security or housing security, as an UCEDDs we need to be positioned to help them make those connections and that means we have to focus on being well connected with those resources in our own states, who those people are and how to access them to support our families.

>> DARLA GUNDLER: And then to identify your state resources in technology and link families and practitioners to resources including training.

Not every part of the state and even in some of the urban areas, families don't have access to the internet, so then what happens?

If Starbucks down the street, on the corner isn't opened and their Wi-Fi isn't working, sometimes families can't access, so not all families have the capacity or want to be receiving -- on the receiving end of Zoom, some people don't know Zoom before this happened.

I think those are some of the things that the new technology and new way we are moving forward, we need to know where are the hotspots, where can families connect and do they know how to use the technology?

You give them a chrome book, it's not a laptop, it's a chrome book, it's a little different, or you are using a iPad, I think we need to think differently knowing where the resources are and making sure the families have access to the resources because that seems to be one of the other challenges.

Trying to do a classroom on a smart phone, it's just not working.

So we need to think differently about what are the resources within the state and is there money to help support families to have access if they don't currently have access to the technology.

>> MOLLY COLE: Families have been clear to us what they don't need are pages and pages and pages of resources like who has time to go through all those?

What they need are easy to use very quick tool kids, ways that can help them navigate

this, whether it's a tool kit on some specific delivery models, whether it's a tool kit on specific platforms and programs that a school system in their community might be using.

The same for practitioners.

I will say this, families have expressed some discomfort in the sense that they are not feeling that all of the practitioners who are working with them are well versed in doing distance learning and, so, the families aren't feeling that they are necessarily receiving services from people who really know how to do this delivery either.

Tip sheets for practitioners would be welcome for everybody so that the families have confidence in the work that the practitioners are offering them and that is offered in a very easy and simple to follow way.

Make this as simple and unencumbered as possible, not sifting through pages and pages of resources to find what it is you want.

>> DARLA GUNDLER: And then month vied technology assistance to staff on how to meet family's needs and the first thing we need to do is listen to the families.

When they are not answering the telephone, just like when doing home visits or kids were coming to school, they are telling you something, so we need to listen to them and sometimes it's not listening to the words they are saying but by their actions and I think that is one of the things, what can the UCEDD do to support that?

>> MOLLY COLE: We talk about providing training on coordinating and collaborating on service delivery options and technologies so that there is some remote learning happening but done in a teaming way.

I can't tell you, we have heard from more than one family about the challenges in having maybe three different practitioners serving one child, all using different programs, different applications, different sets of things that the family has to learn how to operate and how to work.

They really struggle with this, and, so, what we are looking for are ways that the teams coordinate their plans for a family so that the families aren't bombarded from every direction with, you know, a set of worksheets here and different program here and a different application here and the poor family is struggling to make it all work while having two or three kids learning in their household, it can be incredibly difficult.

Training that focuses on coordinating and teaming and really thinking through what the service delivery options would be could be a great help to families.

>> DARLA GUNDLER: And then develop strategies to help service delivery teams to measure progress.

If you are going to ask the family to collect the data, that's not the answer.

Families should not be collecting the data, they can provide you input but shouldn't be the person collecting the data.

One of the families said, well, they've given me a sheet, because they need it for their reporting.

You need to have a conversation.

It all goes back to how are we having conversations.

>> MOLLY COLE: The next is to provide opportunities for stakeholders to come together and use their experiences to plan from proactive activities, family driven models.

Here we are, we know that there is a high likelihood that we will have quarantine again in the fall.

We got caught in a lot of ways unprepared at this point.

We can't go into the next round as unprepared which means that we have got to start to listen to the experiences of families and other stakeholders and providers and really begin to be proactive in the way that we prepare for the next round.

So that we have the right technology.

I hear from other families who will tell me they are not, they would really like to have a phone conversation but they may be dealing with a provider who does not want to release their personal information to anybody.

Are we preparing people to have access to appropriate equipment in their home offices that protects the confidentiality of the families they may be working with.

Have we really thought through a lot of this kind of work that needs to be done in the long run.

So the best way to do that is to pull some stakeholders together, start to have those conversations, listen to the experiences that families have had and be better prepared before this happens again.

>> DARLA GUNDLER: In doing that provide ongoing self-care routines and techniques for those that we serve for families and persons with disabilities because now is the time to start creating some of these tools if we will to use as a lens to think what kind of resources can we provide to make sure families are exercising, are there apps, things to make sure they have access to.

We were all very quick to have free internet access or free this or free that but it was only for a short time so what did we learn from that?

How many people actually took advantage of some of those things?

And I think no one ever thought two months later we would still be doing this.

I think we really need to talk about self-care for our staff and ourselves but are we taking care of everyone in the household?

To think differently how we provide self-care routines.

>> MOLLY COLE: And then lastly, if there is a theme, this is the theme, to be proactive, not reactive.

To get ourselves in a better position as UCEDDs and LENDs to really be responsive in a way that makes sense.

So in order to do that we would like to recommend embedding disaster planning objectives into the five year UCEDD plan and include people with disabilities in the process so those people who have been affected.

I can tell you, Mary Beth alluded to this when she said we had a very skewed sample and we did have a skewed sample but we can tell you based on the people on our calls and based on the families I'm in contact within Connecticut, families of color have been disproportionately affected in sickness and in death and are really, really struggling with a lot of the trauma that is going on.

We need to be able to take those experiences and do a better job of planning and supporting and being prepared to do that.

We can't do this again to ourselves or to the families and individuals with disabilities that we care about, we have to be proactive in the way that we approach disaster

planning in the future.

>> DARLA GUNDLER: Nothing should get back to normal because normal was not working.

If we go back to the way things were we have lost the lesson.

May we rise up and do better.

So now we have a poll, we'd like to know who is on the call so we can get a better sense so we can react as we react as we can.

Who is on the webinar?

UCEDD.

>> The UCEDDs and LENDs have an unique opportunity to demonstrate leadership in reaching out to those who we most care about and also have the expertise to help practitioners also meet the needs of families, so hopefully we will take this seriously and start talking about some of the things that are working and some of the things that we have this opportunity to step into.

One of the things and this is why I was so thrilled, these parents are doing this for us, is the fact that we -- unfortunately Rud Turnbull is not with us, he is here in spirit, he will be with us in the next one, one of the things I think is such an opportunity is to look how we create an early childhood workforce who is truly important and we've heard that from families and practitioners who are now able to spend time getting to know a family and to listen to them.

So that is what we don't want to lose.

Can I ask somebody to just mute, please, we are hearing a little background noise.

Thank you.

So what is our result of the poll, Darla?

>> DARLA GUNDLER: Anna, do you have it?

Can you pull it up?

>> Anna: Sorry.

>> DARLA GUNDLER:

>> DARLA GUNDLER: I can't see it.

>> Anna: I'm pulling it up.

>> DARLA GUNDLER: Perfect.

Ann, this is important information from us.

>> Mary Beth: 32% are families either working at an UCEDD or family of a child with a disability, there are lots of other and lots of PTI or parent center or parent to parent staff as well as those add UCEDDs and LENDs and state administrators who can help make these partnerships work in the era of COVID.

>> DARLA GUNDLER: Great.

Thank you.

>> Mary Beth: I will get out of screen sharing and leave it to you to get us to screen sharing.

>> DARLA GUNDLER: There are a couple questions and comments in the chat I wanted to address and Ann, Ann's words of wisdom because it does say in the age of protecting confidentiality how is it best to connect parent to parent for monitoring. And then another question or comment is the new Mexico family infant toddler program has put together some guidance for families of practitioners how to prepare for a virtual

home visit, thank you for that resource.

And then this is an interesting one, you all mentioned sitting at a Starbucks and having a laptop or chrome book, provider apps can't be assured privacy and confidentiality sitting in a public place, even a car, so as you are doing your progress notes, that's something to think about, you are not protecting a family's privacy doing that.

And connecting families for virtual learning, question mark.

Okay.

>> ANN TURNBULL: I can jump in and share some thoughts.

There was a question, Darla, go back to the first question, let's make sure we address that.

>> DARLA GUNDLER: Is that the age of protecting confidentiality?

>> ANN TURNBULL: Was that it?

And can you say the whole question?

>> DARLA GUNDLER: It says in the age of protecting confidentiality how is the best to connect parent to parent for monitoring?

>> ANN TURNBULL: And parent to parent for monitoring, monitoring what, I wonder.

>> DARLA GUNDLER: The person asked the question can you please unmute and explain to us exactly what you are looking for so Ann can answer appropriately?

>> Burris: Monitoring each other, I presume.

>> DARLA GUNDLER: Okay.

>> ANN TURNBULL: I could not hear that unfortunately.

>> Mary Beth: I think what you were saying, Duke, if I may use your name, I think you were saying again how can you match parents or set up a parent to parent when in the age of confidentiality how can parents be put together and you certainly have lots of experience in parent to parent models.

>> Duke: Yes.

>> ANN TURNBULL: One of the things that comes to me, I've not directly delivered parent to parent services but certainly have worked with there's programs for years, but I think often confidentiality or HIPAA, I hear so many times we can't do that because of HIPAA.

When I wonder what if both families gave consent that this is something that they want to do and it seems to me that in this age when we need to work virtually, maybe we are going to need to think about getting more consent from families to share things because many families would rather have the parent to parent connection than to have their name held strictly confidential or they might prefer to be in the Starbucks and have an opportunity to work with a provider, perhaps even if someone else at another table heard some of it because that -- or they may not prefer that but I think in this age where we have to think outside of the box on confidentiality, we are going to have to weigh the benefit and the risk and to ask families is the potential benefit sufficient for you so that you will give up some of the confidentiality in order to get the benefit. That's my take on it.

I was a Hospice have it for with an elderly woman with significant disabilities, her daughter was rarely able to visit and I started taking a video of her at every visit and sending it to her daughter.

Her daughter absolutely loved it.

And I got into a lot of trouble with the Hospice program because they said I was breaking HIPAA, I had never thought about that.

I just thought I was connecting the family and I said, well, if that's HIPAA, her daughter loves it so much, let's get a signed release since her daughter has the medical power of attorney and the legality to make decisions for her mother and they said, oh, no, we can't do that, it's HIPAA.

Maybe one of the gifts of COVID is to look at some of the things that we have gotten boxed in the corner with and to say how do we save the spirit of confidentiality while we are getting the benefit of family connection, so those are some of our thoughts.

Let me respond to a couple of other things on the top 10, thank you, Molly and Darla for putting those together.

I've been doing a lot of thinking about this since Mary Beth asked me to participate about the whole UCEDD network.

Oh, my gosh, there are so many resources in the UCEDD network and here is a thought, could this group on the phone together, could we take the top 10 and different UCEDDs that one, if we just take one it's not overwhelming, if we take 10 we don't have time to do it.

Or if one is too much could two or three UCEDDs work together and take one of the top 10 and develop the five best resources?

People don't want the 25 best resources right now.

I'm always remembering that phrase in trying to get -- trying to get a question answered in the day of information overload on the internet is like trying to get a sip of water from a fire hydrant.

This morning I looked at a lot of disability organizations' websites and people had jumped on COVID, from every organization on their home page has a link to COVID resources and I looked through a lot of those resources and there are some really good ones and I was really excited.

For general disability, you know, such as the parent information and training centers have some excellent resources and Wright's Law has excellent resources and any number of programs and then disability specific organizations, autism, ADHD, whatever, they all have their resources and I want to challenge you, let's do something, you know, let's listen to this webinar and participate and think about it, but when you leave we want you to take action and I'm wondering if somebody might step forward to say, gosh, I would coordinate, you know, getting a list of the UCEDDs that would volunteer to get the five best resources on each one of these top 10.

And then put that together on the AUCD website and then make it available for family organizations, I'm thinking particularly about resources helpful to families.

Let me tell you a couple of things that I found.

I looked at the Council for Exceptional Children website which many of you know who are in education the primary special education professional organization.

In the Connecticut survey special education was identified as the No. 1 challenge.

So what does the Council for Exceptional Children have?

They had a wonderful tip sheet for families on supporting their children with disabilities and virtual formats.

This was put together by the Florida Inclusion Network.

Some of you may know who are in education that at Vanderbilt they have a program called the Iris Center and it develops modules for higher education faculty teaching special education.

Listen to this module: Parents supporting learning during the COVID-19 pandemic. Fabulous module.

And probably a lot of families rather than going through it themselves might enjoy an UCEDD-led social support group where they are going through it with other parents and sharing what is working for them in providing homeschooling.

Wright's Law, if you have any, parents of any law question about COVID, probably right now the Wright's Law website is their best go-to place, they are having a free seminar tonight with four attorneys which is entitled Special Education During COVID-19 and it is answering the legal questions about what happens if the IEP is not being followed? And what about extended school year?

And related services?

So how do families find this?

They can't spend the morning doing it like I did.

So I want to challenge you as an UCEDD network committed to families that you find -- you pare down the fire hydrant and find the top five for each of the top 10 and that would be an enormous contribution you could make.

Some of you who are trainees, that would be a fabulous project you could put on your resume and talk about in your job interviews in how you took national resources and put it into the hands of families.

I'm not so much of a Facebook person myself but I wonder about Facebook communities that UCEDDs might sponsor for families so that they can easily connect with each other, share resources and that kind of thing.

I wanted to share two other points.

Today in my email just like you may have received the Disabilities scoop newsletter.

It will be talking about getting money, the No. 2 Connecticut resource, maybe -- Ruby, the No. 1 or No. 2 Miami, when I said Connecticut resource, I meant Connecticut challenge from the data and, Ruby, at the top of your list was also financial challenges. This is a huge stimulus bill.

Who can sort it out?

If UCEDD would take it today and break it down into practical steps on what families can expect and if families don't get their -- this says -- let me see if can I find it quickly \$1200 per person cash payment up to a maximum of \$6,000 per family, can you imagine how helpful that would be?

But if people don't know about it and this is for Americans earning less than \$75,000 annually, families need to know about this but they probably won't know unless people such as yourselves make that available.

I want to mention two adult issues, we've talked mostly about children and that's very appropriate, but as Mary Beth said, I think, Mary Beth, you said there was a person 83 years old that responded.

Can you imagine a mom or dad 83 years old trying to figure this out for their 60-something son or daughter with an intellectual disability who lives in their home? Interacting with my parent friends who have adult sons and daughters with disabilities,

the two biggies over the last two months, one has been the hospital policies. If an adult with an intellectual or developmental disability who is unable to communicate on his or her own goes to the hospital with COVID, can a parent or a care giver be there?

That is -- in many states that is being blocked, that person is going to go alone and the nurses and the medical staff would have no idea about -- probably would have no idea how to best support that person.

Families of adults are in frenzy about that.

The best thing that has been developed so far, you can find on the Bazelon Center website, the Bazelon Center is a mental health law center and they have worked with four or five other national organizations in developing what they call an evaluation framework for hospital visitor policies and it provides parents with their rights and with what different states are doing and I tell you what, sadly my son with a disability, Jay, died very suddenly when he was 41.

That was 10 years ago, he would be 51 if he were still living.

If Jay was still living one of the first things that I would do before he got COVID, if he was unlucky enough to get it, but while he was healthy, I would take these policies and I would talk to the hospital administrator in my community and I would have it completely understood that if he got COVID and if he went to the ICU either his father or myself could be there.

Don't wait until it happens when you are in panic and then try to negotiate.

Families need to know that.

Another thing that families are telling me and that I have been trying to help with over this last two months is support staff for adults in supportive living and in group homes are getting COVID or they are isolating and they are not coming to work because they are keeping themselves and their families safe and the question is can they still be paid?

Because so many families, my neighbor is one of these who has now worked about 18 months to get the right support staff, the direct professionals with her son with very intensive needs, and if they are not working, they are often not getting paid and they can't afford to not get paid.

And, so, families are very scared that those folks are going to find other jobs or they are not going to come back and they are going to have to start all over after the quarantine.

So what UCEDDs need to be doing to really support community living is to work on state policies that allow direct support staff to be paid while they are quarantining so they can come back when the quarantine is over.

And there are policies that have been developed, you can look at the website of the Ark of the U.S. that has model policies on what states should be doing.

The center for Medicaid and Medicare gives states flexibility.

Any family friends who have been advocating tell me it's appendix K that give families a flexibility through appendix K in unusual circumstances to change their regulations and I know the state of North Carolina with a lot of parent advocacy has now established the direct support professionals when -- so they can still be paid for the same number of hours they would have worked if they were not quarantined and that saves them to

be able to come back.

So those are some of my comments.

I did notice, Larry Adleman, you are on this webinar, I saw your name unless you have gone -- I saw your name at the very beginning.

Are you still on, Larry?

>> Larry Edelman: Yes, I'm here.

>> ANN TURNBULL: Larry, you have developed some great videos I have been seeing in my email and clicking into and this is a great resource for UCEDDs to know about.

Would you share what you have done and how people can get access?

>> Larry Edelman: Sure, I'd be happy to.

Since the pandemic and stay at home orders and, you know, the ability of us to have face-to-face, person to person contact with families we started to produce videos with programs who had a head start in using video conferencing to reach families who have kids who are eligible for part C early intervention, so what we have been doing is working with the family and the practitioner and having them video record their sessions and then I have a Zoom with both the family and the provider to interview them so they could talk about their experiences and talk about what works and doesn't work, how the visits are helpful for the families, what is difficult, what isn't.

And there is a collection of about five of them right now and I just finished one today and we are doing one totally in Spanish that should be done next week, and they are all on the ECTA, Early Childhood Technical Assistance website and if you go there to that website, you can just Google ECTA and you will get there, there are things there for early education providers and section C providers, we are trying not to talk so much but videotape illustrations, what does it look like when a practitioner-family video conference together, when they don't, we are trying to do some research and very dynamic action research about how the families feel about only having telephone contact because there are still programs in the country that are really resisting using video conferencing.

>> ANN TURNBULL: Thank you.

Let's get those on the AUCD website, that's a great example we all share the work, we all work on the top resources, let's make sure that every UCEDD knows about these videos.

I just thought of one other example I want to share, then I will be quiet was on a phone call with a parent friend last week whose son is transitioning from elementary to middle school and he has had some significant challenges related to being in seclusion, inappropriately, in elementary school and has a lot of trauma from that, so it's very important to find the right middle school for him.

On the IEP, the woman conducting the meeting who was the special Ed coordinator was driving, she had had a family sickness and she was driving on the highway while she was facilitating the meeting.

At one point a car pulled out in front of her and she screamed some curse words and panicked that the car was going to hit her during the middle of the IEP meeting and I thought what has happened in COVID that we feel we can be that informal?

How could it be that someone could facilitate a transition IEP meeting while driving and

then be screaming at another driver?

And then this is transition.

Whether it's transitions from early intervention to preschool or preschool to kindergarten or elementary to middle, middle to secondary, secondary to adulthood, there was no opportunity for the mom to visit the school and see what that was like. And, so, just virtually thinking about transition, how do we help programs think about preparing photographs and preparing videos so that parents who are not able to visit that next site in person can now virtually visit and that we don't relax the rules so much -- I was saying at the beginning maybe we need to relax some rules but not so much that it's okay to facilitate and be the chairperson of an IEP meeting while driving on the highway.

So those are some of the things I've been learning from my parent advocacy parent friends who right now are needing all the support we can muster to help them make wise decision how to use their time.

>> MOLLY COLE: Thank you.

I want to comment, there were a number of comments that came through the chat box relating to connecting with parent organizations in your state and if you haven't read those comments please do so, but when we talk about networking and collaboration, collaborating with your local parent to parent, collaborating with family voices, local PTI, a number of other local family associations.

We have one in Connecticut that is active with children mental health, make sure you are connecting and dialoguing with those groups and bringing them to the table as you develop your disaster plans because they know what is out there and they know how to connect, so, just make sure that you make those linkages as you build your collaborations.

>> DARLA GUNDLER: I think one of the other things I want to say, one of the comments that one of our friends put in the box is she appreciates the disparities discussed earlier but then she goes onto talk about I'd also like to know how families who have low access to technology and low technology literacy can be supported in gaining access on both fronts at this time to support their children and I think we make assumptions that someone has a smart phone, that they know how to download the apps and use all those apps and sometimes you have to register, you have to put a credit card in, some of them are very complex.

We can't assume that everyone knows just because they use a smart phone how to use all of the technology.

Then the other comment I saw was around families, it's great to have the websites if you have the technology but most are in English, how do we make sure families have access to websites in multiple languages and they know where to go to get resources that are informational and explain it in a way that they can actually understand.

>> ANN TURNBULL: One of the things I saw this morning when I was doing my search, let's see, where did I find it?

On the Center for Parent Information and Resources, that is the technical resource center for all the parent training centers.

On their home page they have links to a disabilities rights program in California, one of the early programs called DREDF and I noticed they had documents on COVID in

English, Spanish and Chinese.

They may have had other languages as well, those are the ones I just saw so any internet search we do for resources we need to be particularly careful looking for different languages and recognizing that the average reading level of people in the U.S. is eighth grade, many people don't read at all or read much lower than eighth grade, that is average.

USA Today is written at 9th grade level so that gives you an idea what 9th grade level is, so we need to especially look for resources that don't take graduate school training to comprehend.

>> DARLA GUNDLER: Other comments, questions, anyone want to unmute and ask a question or make a comment?

>> ANN TURNBULL: Let's hear from some of the families that are on, it would be great to hear from some of the families whether staff at UCEDDs or not on some of the things that you were seeing and some of the gold nuggets you've discovered of what is working?

What can we learn from your experience with success?

>> Doris Maldonado: Can you hear me?

I'm in Connecticut and I am very fortunate to be affiliated with the UCEDD, very aware and informed by them and other -- I'm an advocate and I have vast experience, I have children with special needs, I am a person with disabilities as well and I became a certified teacher after being a paraprofessional so I could support my children and others in that context and all three my children are thriving because of it, the fault I'm finding in many of my communities that I represent is the lack of parent training that is empowered and mandated by the IDEA and no one is familiar with it so our parents are struggling with the technological age more so than the children they are trying to help and we don't have the facility to provide iPhones or even laptops.

I have some students that still have not received a laptop so they are not receiving a free and appropriate education, public education, we don't even have a representative on the reopening of the state as far as special education is concerned.

So being an advocate and knowing what your rights are, I've been privileged to be trained by several of the trainers that are on the call now but just tapping into the resources, they are part of many organizations, faith based as well, so trying to tap in and training yourself and being knowledgeable, being involved in what is going on legislatively and out there, but it's really difficult.

Myself, as I said, certified teacher, my sons are in high school and they are given too much homework, inundated with too much homework, more than before, just to keep them away from actual learning.

>> ANN TURNBULL: Right, very good points, Doris.

I hope you will tune into Wright's Law website it has such great questions and answers of when the IEP is not being followed what do you do in the time of COVID.

>> DARLA GUNDLER: This is a why question.

There is a task force to reopen schools in the District of Columbia and parents of any children were left off to consult.

>> ANN TURNBULL: I'm wondering about going to the superintendent, to the director of special education.

You know, maybe working in concert with the parent training and information center in the district, having a meeting and saying this is an omission that is not okay, we want to work with you, not against you and we recommend these two people for the task force and when is the next meeting?

Something to take action rather than being regretful that it happened.

>> MOLLY COLE: I think you make a good point, when we are invited to the table and the table is missing the key people that should be there, we have a responsibility, a professional responsibility to open our mouth and say you know what, we can't go forward without the right representation, we cannot do this because it will not be in the best interest of the people we all care about.

>> ANN TURNBULL: Molly, I'm thinking about the mother I was with on this transition IEP, single mom, African-American, felt marginalized by the school system, her voice needs to be at that table.

>> MOLLY COLE: Yes.

>> ANN TURNBULL: We white people need to make sure we are advocating for the representation of families from many different background even if it means that we step off so there's a place for them to step in.

>> MOLLY COLE: That's right.

>> DARLA GUNDLER: I think there is a lot of resources out there, there really is, but one of the comments in the chat box is it's great to centralize the resources, it helps with half the battle.

Families can't be searching all these different sites and how can the UCEDDs be that repository, if you will, collect all those resources, links to different sites but make sure families know where to get the information.

I think that is half the battle.

It says support is needed to make sure we have metrics, measuring actual support for families so it's reaching the hard to reach, just thinking differently moving forward.

>> ANN TURNBULL: One of the things as I look over my 50 years of working that gave me the most gratification was partnering with a number of family leaders from racially and ethnically different background in supporting them to write grants so they could have funding to be in business.

If you can't write the grant you can't mobilize more than just your own energize during the day.

I mean this was 20 or 25 years ago, at that time it was like computers and FAX machines that they didn't have.

But, anyway, what we found is when we partnered with them they taught us so much in what they were doing and they told us how they supported families in the underserved communities and we would put it in evaluation plan and then send it back to them and say did we hear right?

Did we get it right?

That enabled so many to get going.

As UCEDDs we are uniquely qualified to give that technical resource to family leaders so make sure the resources are shared and not consumed by people who know how to do grants.

>> DARLA GUNDLER: We have one parent who would like to speak.

Chioma.

>> Chioma Oruh: Thank you so much, this is such an enriching and fruitful communication happening in this space.

I apologize if what I say is redundant, I've had my family off because I'm literally multitasking as I'm on this call.

I wanted to add that the reality that we as families, especially, you know, with intersectional identities and different levels of preexisting disadvantages, we are not all functioning from the same baseline here.

Everyone is impacted by what is happening right now.

But if you were already struggling and already had, you know, low literacy, low access to technology, were on the eviction list of your apartment building, couldn't find a way to feed your kids, had an open case with CFSA, the child protective services, in a domestic violence situation, these things were reality prior to COVID lockdowns.

And a lot of our families with kids with disabilities are living in these conditions and these are the most disadvantaged families that are not easily recognized and I do thank you for the presentation earlier that made that also clear, that most of the people being surveyed or engaged on a research level are already highly educated, have some level of resource, have some access to agency in terms of, you know, being able to advocate for what they want, being asked to do a survey, so there are different levels of advantages and I'm very concerned with the families having worked with the PTI, if we are saying the PTI -- they are already very lowly invested in, you know, right now like I don't work for the D.C. PTI, I do some contract work for them but I have to literally step out because I couldn't sustain my family doing the work, I had 150 case load taking care of my own family and couldn't pay the bills.

I had to find a way to make it work for my families and do other projects and find other ways to leverage and market myself and I do have privileges that I know a lot of the families I work with don't.

But it's still a duty to recognize that like when conversations are being had, the family -- the need for family centeredness needs this, value the work of the PTIs, value the first responders, you can hear my family in the background -- hold on.

So, you know, bottom line I can keep going on and on, I want to stress that like we can talk about putting resources on a website which is helpful for an advocate like me that can touch 10 other families but those are things that I'm doing, who measures if I'm doing it and doing it well, if I'm resourced to do it, if I need help doing it.

That goes with the PTIs and any other individual advocate working with impacted communities and I don't know where that conversation can be forwarded, where real resources can be deployed on the local level, where families are going to need support, are going to need trusted organization and, you know, advocacy efforts to help them and I want to give that reality check to the situation, it's not enough to just put resources in, we have to recognize these are multilevel, even in the political engagement.

Like I don't know, last thing I will say, I don't know in terms of, like, I've train as an organizer, I'm a political scientist, you don't create a campaign without money.

If we say we need to get XYZ seats, that requires political capital to have that engagement with the families and no one will make a call for anybody if they don't have

a relationship with you, if they don't trust you, if they don't know to be able to help your bottom line and that requires investment, so I just want to say that.

>> ANN TURNBULL: Very wise comments.

>> MOLLY COLE: And thank you.

>> DARLA GUNDLER: Molly, you are on mute.

>> MOLLY COLE: I muted myself because the dog was barking.

But here's the thing and Mary Beth would -- she is going to cringe when I say this, but Mary Beth in Connecticut has a long history of putting support into families and family organizations and the trust and the relationship that goes with that is really valuable and I'm going to say as UCEDDs we all need to embrace that perspective that we do have a responsibility to build up and connect with family organizations in our states and help them to be at the table with us, so, we are just very fortunate in our state, I trust that some of you around the country are doing the same thing but it's a long, a pretty long legacy that we have in Connecticut, I would not be doing what I'm doing if it had not been for that commitment with the UCEDD way back.

>> ANN TURNBULL: And, Molly, you were encouraging us earlier to be ready for the next wave of COVID.

>> MOLLY COLE: Yes.

>> ANN TURNBULL: Now is the time -- Mary Beth has been developing, Molly, you and Darla and others have been developing these relationships for decades but if UCEDDs don't have those relationships now start now building them for fall, not spring, because it really does take the evolution of trust and it was a lesson to me when we started this work from the University of Kansas Beach Center and people of color would say why should we trust you?

I wasn't aware of the anger and the resentment and I should have been, I'm not proud of the fact I wasn't aware but I was made aware and I think if developing the kind of partnerships we need to truly be trusted partners with family leaders and families from underserved communities, we are going to have to listen and not be defensive and recognize that the mistakes have been made in the past and that how we can move forward together in trust.

You know, and today is the first day of the rest of our life to do that.

>> Mary Beth: Thank you, Ann, Darla and Molly and all the families.

I think the top 10 things that Molly and Darla put together was to look at your five year plan for UCEDD for preparedness.

In the northeast we are still quarantining, I don't think we will have a great summer, I want to echo what Ann said but I am going to challenge the UCEDDs and LENDs to follow an objective, preparedness is how you engage families from diverse places, how do you give money to those organizations so they can do some things.

And I'm going to ask all of you because we do have to sign off in a very few minutes.

In your evaluation which, of course, you all are going to do, you are going to let us know if maybe our next COVID webinar should be talking about how to reach out to diverse families especially around the equity issue that so many of you brought up that we are seeing, we know that if families who have needs are struggling, the families who really don't have the technology, don't have the time, are trying to keep a job, how do we do things different?

I go back to the slide that Darla and Molly did which is we need to use this opportunity to learn and this is the time to learn.

I think that everybody is giving each other a lot of degrees of freedom because we know that things are not the way we want them but let's create this future.

And, so, I need to hear from you because we are committed to continuing these early childhood COVID webinars more frequently, we normally did once a month, we are going to twice a month, if that's the next topic I can put my parent expert paneling together to bring some of you onto see if we can come up with strategies UCEDDs can do to help families who are more diverse than the ones we typically see sitting around the table so let us know if that would be helpful.

>> ANN TURNBULL: Thank you, player I Beth, for all you do to be an advocate for families.

You are nonstop 24/7/160 degrees, all of those things and we are grateful.

>> Mary Beth: I'm in the great company of the three of you and those who inspire my, most notably all parents trying to be a good parent in this very stressful time.

I'm going to that is correct my panelists, Molly and I also should say the reason Molly is acting associate director, many of you don't know Molly retired and she came back and is working more days than she is getting paid for just to keep us going, especially our UCEDD.

And Darla, who is keeping our ECPC Early Childhood Personnel Center going in the days of COVID and, of course, Ann who has been our inspiration for many years and keeps us focused on listening to families.

>> ANN TURNBULL: And my husband Rud was supposed to be here and he had surgery last week that ran into some complications and thankfully he is fine but he just got home from the hospital late yesterday so he was sad to miss you but he will be here in two weeks.

>> in Mary Beth: We will plan for two weeks.

Email me, it's Bruder, let me know what will be most helpful, how can UCEDDs and LENDs, training the next generation who will get the best training that there ever could have imagined by being trainee's in this day and age.

I thank you for your time and we will see you in a couple of weeks.

>> ANN TURNBULL: Bye, everyone.

>> MOLLY COLE: Bye.

>> DARLA GUNDLER: Thank you.

[Webinar ended at 4:28 p.m.]