

Association Of University Centers On Disabilities (AUCD)
COVID-19: How Ucedds And Lend Programs Can Partner With State And Local Early
Intervention And Special Education Systems During This, And Future Pandemics
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Remote CART Captioning

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>> Sorry for those who logged in early, we know you can hear us now. We try not to say anything incriminating.

And for those joining us, we'll be starting in five minutes.

>> Mary Beth and Maureen, are you both ready?

>> I am. Thank you.

>> Me too. We hear an echo.

>> That's not good.

>> Hello. And welcome to "COVID-19: How UCEDDs and LEND Programs Can Partner with State and Local Early Intervention and Special Education Systems During This and Future Pandemics."

My name is Alex and I'm here at AUCD. We would like to thank you for joining us today. I would like to address a few logistical details. Because of the number of participants, your audio lines will be muted throughout the call. However, we will unmute your audio lines at the end during the Q&A. You can submit questions at any point during the presentation via the chat box in the webinar console. You can send the chat to the whole audience or the presenters only. We will compile your questions throughout the webinar and address them at the end. This webinar is being recorded and will be available on AUCD's webinar library. Also there will be an evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar and provide suggestions for future topics.

Now I'm going to pass the mic over to Dr. Mary Beth Bruder, chair of the Early Childhood Special Interest Group. Mary Beth...

>> MARY BETH BRUDER: You have many, many precedents for all of us, I think in the ten years we had this special interest group, this has probably been the most anxiety-provoking time we all have lived in. And not the least of which is anxiety about the families and their

children who we serve through the UCEDD network and the LEND network. I was very, very happy that two of my very good friends, John Eisenberg and Maureen Greer agreed to come on to talk to us about the partnerships that many of us already have in our states with our Part C for early intervention and Part B for 3 to 21-year-old programs, both at the state and local level. I do need to start out with one disappointing piece of information. John Eisenberg is not able to join us. And that is primarily because of the policy that was sent out in a letter from Secretary DeVos's office to Congress, Secretary DeVos herself, about the lack of waivers being available for FAIP, free appropriate public education. John, however, will be on with us in two weeks, which is the 12th of May, same time, to talk about the Part B program. He is a LEND graduate affiliated with the UCEDD in Richmond, Virginia, my first UCEDD I worked with and worked on the grant for. So he has long roots in our community. So he wanted to give his apologies and to tell you that he would be here except for this situation that occurred yesterday. And some of the information that has to get out in the right way and not distorted to the special ed directors across the country. So today's webinar, just to put a caveat, we are not going to be talking policy. We have just extraordinary policy people at AUCD, as you all know, who are doing weekly and then more frequent policy seminars. They are the folks who interpret policy. We're here to talk programmatically. It is my great pleasure to introduce a good friend of mine who is one of many teachers who helped me get through the day. Maureen Greer has been involved in early intervention since its inception, but even earlier because she was a mom who came into the situation of having a child who she had developmental questions about.

So with that, Maureen had really added on to her resume all the work she has done not just on behalf of herself, her family and the families in Indiana, but at a national level, both through the maternal and child health network of which she has been a major player, and more specific to Part C she has been the founder and executive director of the Infant and Toddler Coordinators Association that oversees the directors, or coordinators I should say, of the Part C program. She works with them closely and works with OSEP very closely. Maureen always has a lot of data, that's why I love her. And she's going to be presenting some data. We're going to change up a little bit of the question and answer. Maureen and I present a lot together, so we're both going to be responsive to questions. Again, we're talking about programmatic application of what's happening in the Part C program. A reminder in two weeks John Eisenberg will be doing this same webinar specific to Part B. Apologies from him. Not to take away from what Maureen is sharing with us, I turn it over to Maureen...

>> Maureen, we can't hear you.

Mary Beth, can you text Maureen?

>> MARY BETH BRUDER: Yes, I can.

>> Sorry, guys.

We can blame everything on COVID.

>> We could do that.

>> She was just here. We were just talking to her. She could have been the reason why the...

>> Under the presenter notes it does say she's muted, that somebody has her muted.
>> She's unmuted, so...

She just got booted out. Can you text her that she got booted out.

Sorry, guys. Welcome to technology. Sometimes we have this little problem.

>> Maybe she's getting back in.
>> She's getting back in?
>> All right, Maureen...

>> MAUREEN GREER: All right. Can you hear me now?
>> Yeah, we can!

>> MAUREEN GREER: All right. Sorry about that. I don't know what was wrong. Anyways, I think we all need to sense -- what I started to say was that in this time as we're all, many of us are in our homes and separated from friends and colleagues, the opportunity to come together to have these kind of conversations becomes even more important. So I'm really excited not only to provide some information around Part C and how it looks nationally, but I also see some of my Indiana friends. I see Montana friend. This is in like in many ways coming home. I started a lot of my formal work at the UCEDD and LEND program in -- a long time ago. I won't say how long. It's delightful to come back and always fun to talk to you all.

What I thought we would do today is talk briefly a little bit about what do we know about the current status of state Part C systems and what are the key issues that they're dealing with? One of the major issues that we began to have a conversation with last week -- and I assume we're going to talk some more this week -- how are they preparing for reopening? In many cases reopening is going to be way more difficult than it was to close. And then finally, how can UCEDDs and LEND programs provide resources and supports to Part C? I think that you can be an integral part of moving forward as the system and we'll look forward to your questions and comments.

So starting, let me give you a little bit of background. As executive director of the Infant and Toddler Coordinators Association, one of the services we've been providing to members since the beginning of this pandemic are calls, phone calls. We do Zoom calls once a week. The very first week in March we did -- towards the end of March, we did three calls in one week. So we scattered them across the time zones so that everyone would have an opportunity to join. And since then we have been doing weekly calls. Thursday at 3:00 is our time to gather. And we have been averaging 49, 47, 48 states calling in to that call. And some of it is they just like seeing each other. The Zoom has created a community. But we have been doing joint problem solving, checking with each other, finding out, you know, sometimes it's the funny thing. Sometimes it's a real challenge or problem. They have been doing a lot of sustaining each other and in doing shared problem solving. So one of the very first things that we talked to them about is just what was the status of their program. So we wanted to know, are your agencies open? And so you can see that 94% of the states responded that they're open and working from home. And there were 6% that simply didn't answer the question. So we don't

know where they are. When we looked at local providers, you see the variance across there. So some providers are closed. And, you know, we can -- that can be a challenge. Most providers are open with modifications. So as you all know and experience, in many states, no face-to-face interaction is allowed. You're starting to hear a little bit now of states, governors opening up a little bit. We haven't seen or heard of any Part C system that is opened yet at all. And then in some states, some local providers that were still doing home visits. And that's consistent with the different state incidence rate and looking at what the governor -- what kind of restrictions the governor may have put in place? I will tell you that open with home visits is obviously a very small percentage. But there are some where that is still ongoing. When we talked to them about what were some of the key issues, they really fell in four categories. And so we'll talk a little bit about referrals and eligibility, service delivery, transition and finance. Those were sort of the four large groupings of issues that states are dealing with. We'll give you some data to go along with each of those as well as some of the conversation.

So around referrals and eligibility. So these are some of the questions that states have raised. If an agency is closed, does the 45-daytime line start? So you start to think about just basic operations of how do you begin that process if you get a referral?

I would tell you that nationwide -- and I think I have a slide in here later -- referrals are down about 50%. So we expect that as pretty comparable. Some have reported more and some a little less. But the issue really became around -- I would tell you that one of the overlying questions that was asked was simply, is it even right? Is it ethically right to even do home visits right now when we could endanger both the child and the family, especially where we have a vulnerable child with health issues? And what about the vulnerability of the providers? So that was sort of an overarching question. In terms of eligibility determination, there were a lot of issues related to that.

So if I have an eligibility tool...

>> AUTOMATED VOICE: Your microphone has been TURNED ON.

>> MAUREEN GREER: you hear me?

>> We can hear you.

>> MAUREEN GREER: Do you determine eligibility if your eligibility tool requires face-to-face interaction? What happens about verbal consent versus written consent? How do we handle that when we're not allowed to see each other? So a lot of questions that states have been grappling with, they use these Thursday calls to really begin to say, how are you doing it in your state? What does it look like in a different part of the country? So really beginning to do problem solving.

One of the very first things that we have discovered is that the bottom line to all of this is that states have to make the determination to do what is in the best interest of children and families. And somewhat, to a certain degree worry about compliance issues and protocols when we get through to the other side of this.

So we asked then, how many states have made modifications to referral and eligibility process? 62% indicated that they had. And 38% said no.

Well, as you all know, it's -- it could be easier to make an eligibility determination if a child comes in with a medical diagnosis. It becomes a challenge if we think that there's a developmental delay and we have to figure out how to determine percentage of delay. Now, with the use of telehealth, we can observe families, whether we do Zoom sessions or all of the different platforms that are available. But we can actually see that child. We can ask the family to prompt them with a task. We can use our observational skills to really figure out and determine whether the child meets the criteria. We have the option in some states to look at informed clinical opinion, to really decide, based on the presenting information, do we believe that that child meets eligibility criteria?

And so states have really looked at innovative and I think creative ways to figure out how to determine whether or not a child is eligible. I think the thing that excites me or pleases me the most is that states are erring on the side of a child. So if there's ever a doubt, they seem to be looking at let's make the child eligible for now. We commit that we are going to go on for -- when we can go face-to-face, we'll come back and do a more extensive evaluation. We can make any adjustments to the IFSP or service plan if we need to. But really looking at how do we make sure to the best of our ability that we incorporate that child and family and wrap what services we can around them.

Again, here is the slide I was talking to you about. 62% of the states that were on the call last week figured out -- estimated that probably the referrals were down about 50%. You had a smaller percentage at 75%. And you had some at 25%. But clearly for many families right now, this may not be their priority. They may have lost their job, they're struggling doing homeschooling with their other children. And just right now may not be a good time for them.

The other thing that I want to talk to you a little bit about in terms of service delivery is if eligibility can be determined how to address state service provisions. Have there been conversations with CMS? States have been extraordinarily successful in working with their Medicaid office, CMS has come forward very clearly to support the use of telehealth during this crisis. There were a number of states that had actually already had permission from Medicaid to do that. So we're looking at telephone consultation. We're looking at a variety of platforms. We're also really beginning to look at families actually like telehealth and they like the ability to be wherever they need to be and have that. They can get other members of the family involved. We are starting to see reports of changing of practice, perhaps providers who might have been reluctant before around coaching, beginning to see how there could be advantages to coaching.

So it's always important to look at what are those bonus things or the opportunities that come every time we do have a challenge. So we ask them a little bit about how are you providing IFSP services. So you can see using technology, phone consultation. And then there are, for many families, services have been delayed. And some of that may be systemic, some of that is family choice. Families are stepping back and saying maybe not so much now. Once

everything opens up again we'll come back. But I think that we really begin to look at -- I want you to think about this and we'll come back to it at the end. But think about one of the issues that coordinators have been really discussing, are the challenges of inequity when we are doing... using technology. So in some ways we end up with a bifurcated system for those who have access to technology and those who do not. States have been -- tried to be creative in terms of some states are purchasing hotspots or getting equipment or buying a telephone that can be used for that. But in general we have to be really aware of the potential for inequity as we deal with families who may not have broadband, may not have WiFi availability. Families may have limited data on a phone or no capacity to do that.

And how do we make sure that they have services as well as we move through this crisis?

We wanted to know what percentage -- another question we have been tracking is what percentage of authorized services are being delivered. And so you can see the range that is all across the board. 38% of states were reporting that 100% of services were being provided, all the way down to 7% saying 25% of those services.

Now, states are reporting that families are taking smaller bites of services or they may, using technology not need a full hour, or they might like to do two 30-minute sessions instead of one 60-minute session. So states and service providers are being really flexible in terms of how do we accommodate the needs of the family and ensure that the child is getting some supports. But it's also a matter of checking in with the families as well to see how they are doing and how they are coping and how we, in fact, can support that whole family unit as part of our early intervention programming.

Another issue that we are facing and, again, is scattered across the states, there is no consistent way this is approaching. School systems are closed and what are our responsibilities when a child turns three? Do we say, sorry, you turned three, we can't do anything more for you? What will happen to child outcomes data regarding entry and exit? How do we accommodate that? Do we have less data or do we have bad data? So looking at the quality of data and how that will have much more of a long-term effect as reporting goes. So, again, we saw significant variability across states from where you have states that are trying to support that child after they turn three. There are some states where the Part B or 619 program is still taking referrals and doing eligibility determination. In other cases some states are keeping that child in Part C and trying to do -- provide some kind of support. And other states, where their legal system has simply said, you can't use federal dollars to serve that child and therefore you must transition them when they turn three.

So we're seeing a little bit of everything, and, again, everyone trying to do their best with the resources that are available.

Another major for everyone is money, quite frankly. And those who know me know this is an area I spend a lot of my time in. And there's not much you can do without buying or having the funding to pay for the services to pay for personnel, etc. But the first question that we wanted to get information on to make sure that there was some ability to provide services was looking at Medicaid payment for telehealth. I have to tell you, all my years of working with CMS, this

has been the most amazing part of this pandemic in that CMS has bent over backwards to make sure that people could get service. And so at this point there is no state whose Medicaid office has said they cannot pay for telehealth. Now, some have restrictions on what services can be used under telehealth. And others are just saying as long as it's an EI covered service and it's being delivered, we will pay for it via telehealth.

I have worked with OSEP to have conversations with CMS, and, again, amazingly, the willingness of CMS to do whatever they need to do to provide frequently asked questions related to early intervention out to their Medicaid state offices. So, again, a really good response for those children on Medicaid that leaves in many states a lot of other children that need to have their needs addressed. I think the finance issues are significant as we continue to move forward. All states are worried about the loss of providers. Probably a little less so about large agencies with multi-funding streams with cradle-to-grave services where the cost sharing can be substantial, and they usually have pretty strong development offices for fundraising, but worried about the smaller providers, the individual or independent practitioners, the smaller provider agencies and whether or not they can sustain this kind of practice, Medicaid payments, can they hold on long enough to still be there to be available to provide services? What's the impact of unemployment? How many of these providers will be out of business by the time we can reopen? What about the loss of state revenues? For most states right now, they're far enough into their fiscal year that the huge impact may not come this particular fiscal year, especially if we have fewer services and we are serving fewer children. But what happens in our state fiscal year that starts July 1st or October 1st, depending on your state, and how do you end up figuring out what you are going to lose in revenue when we hear and see -- read and see the headlines of states are looking at their budgets and talking about not 5 and 10% cuts, but fairly Draconian cuts. And what will that mean to being able to serve children in the next fiscal year?

So finance is sort of the underpinning of all of these things that really create headaches and challenges for our state systems.

So what happens when we return to regular order? And it's difficult to plan because no one really knows when regular order will happen. What seems to be universal is that until we get a vaccine, which the scientists report is 12 to 18 months away, is what will we do around regular order? How do we go back to providing services? How do we go back or do we go back is more of the question. What is the status of school systems? Some of the initial conversation were here are some of the factors that will influence how quickly an early intervention program could reopen. What is the status of the school system? What is the availability of testing? What do we have for provider availability? What is the level of family comfort with people coming back into their houses? What was clear is that while the state agency may have to ultimately make the decision, they're not going to be able to do that without local provider agency input and also really getting a good sense from families of what and how they want this to happen.

So, again, my comment earlier was, it will be far more difficult to go back to regular order or face-to-face services than it was to shut them down. And there's so many new considerations

that hopefully you, your programs, the LEND programs and the UCEDD programs, can be part of that process of engagement.

So now really to the meat of, I hope, our conversation today is: What's the role of UCEDD and LEND programs? Having spent four or five years as a faculty member in UCEDD and LEND programs, obviously I have a heavy bias towards them. I think that in some states they are vital parts of the state Part C and special education systems. If you are not currently, we hope you will figure out how to become part of that. You have experience and expertise around best practices, around program evaluation, around data analysis that are going to be critical, not only to how do we open back up, but what is the impact of the virus on child outcomes and family outcomes? How do we look at what we need to do differently are the same? What are some of the best practices that we have learned during our stay-at-home period of a time? That should, in fact, be continued, because they're valuable and good for children and good for families.

Can telehealth be a mechanism now that we've learned how to use it better? We all need to get better at it, but are we better than we were when we started? For the most part, yes.

How do you help the Part C and Part B systems with stakeholder voices? With family voices, with people with disability voices? How do we encourage that participation in both analyzing what we have learned during this pandemic and what kinds of system changes we need to see. And then future planning. You are in a wonderful position to look at system thinking and really begin to look at what are some of the lifespan issues that we will need to look at. They're not between the ages of birth and three in isolation. There are lots of other issues that are impacting both that child and that family. So how do we really move beyond a program concept or mentality and really do good system thinking?

And then finally, as we talked earlier about the issues of child and family outcomes. What is going to change with those? What happens... will the outcomes for children during the COVID time, can we isolate those and look at how are they different? How are child outcomes different? Or were they? Were we successful in still helping children to grow and gain knowledge and skills? Were we successful working with families around their outcomes and successful engagement. So these are some of the things, Mary Beth, we wanted to open the conversation with and hear both what is going on in their states and how we might help each other.

>> MARY BETH BRUDER: I switched to the phone [echoing...]

[no audio]

>> MAUREEN GREER: Technology is wonderful when it works and a challenge when it doesn't.

>> MARY BETH BRUDER: I'm back on.

>> MAUREEN GREER: Okay.

I'm sorry?

[echoing]

>> I was working in the chat box, all the problems listening in and the background. I switched to the phone. I think the phone is the problem. At least on my end. So I'm back to the computer. Before we go on, I want any of you who joined late, give apologies from John Eisenberg. He is dealing with a very important situation that unfolded yesterday with Secretary DeVos's message to Congress. And he will be joining us in two weeks with the same topic, which is looking at Part B programs 3 to 21. I hope you can all join us. And to reiterate this is not a policy webinar. We are going to talk very specifically about the information that we just learned from Maureen and talk about programmatic aspects and how LENDs and UCEDDs can partner with our state programs, both C and then the 619 Part B, though we can put some of that conversation in two weeks, same time, same place. But one of the things Maureen and I talked about is this is an opportunity. She closed with the fact that UCEDDs and LENDs we have been involved in service provision from the '60s, really started a lot of the original early intervention programs, have presence with families and lifespan issues, and this crisis, while very, very unique and new and scary to most of us is really an opportunity for us to do what we do best. Which is to collaborate and keep at the center of our thinking and planning those who have disabilities. And in this instance, our very youngest, who are most vulnerable and families who are most vulnerable early on when they're trying to figure out their new life, of course, as well as getting the services and supports that they need for their children.

I want to just comment on one thing that Maureen ended with, which is child and family outcomes. I have been known to be a little cynical. And one of my statements that I always say is that children do develop in spite of us. I do think this is an opportunity for us to really look at what we can do with families in and around the ecology of that family, of how that child can learn and develop within the context that primarily will be controlled by the family 24/7. In the past we have had an opportunity to be in family homes, at least birth to three. We have been able to bring our expertise to them, and we still can. It's just a little different.

I also would love to hear from people -- and we can do this in the chat box, because on it is going to read them, to talk about the inequity that unfortunately this situation is magnifying. The families who are at the most risk are those who live in poverty. Those who may be experiencing violence. Those who may... [audio cutting out]... those who may not have access to technology, or if they do, how do we provide supports and services to their children?

And I want to also just put out there, which Maureen and I also discussed at length, service coordination. It is such a key component of birth to three programs. And at this point in time, I think we all need a service coordinator, at least to check in on our wellbeing. And I think if we can help -- I'm going to give an example. In our medical center, our medical students are not able to be in the front lines. So what they're doing is calling people for wellbeing checks. People who used to be in the clinics, people they might not have heard of. And I said to someone, that's what birth to three does, we do wellbeing checks as part of service

coordination. And as Maureen said, some of our families, that's all they need, a voice at the end of the line knowing they're not alone. And for other families they're ready to start intervening with their children based on what they know their child needs. So Part C is, to me, a beautiful program for lots of reasons. One is because that's where we get to celebrate the individual needs of each and every family. And we celebrate in a way by providing the services that the families want to see and that we can help them use those to help their children learn and develop.

So Maureen presented a lot of very concerning data. And the concerning data is not out of context. The concerning data is how many programs have seen less kids being referred and are actually doing less service delivery. I think a month ago we were all hoping this would be over in a month or two or even three. Now we know we're going to have different ways of intervening with anybody and everybody from schools into homes. I think Maureen brought up some important ethical issues we have. And it's not so much the ethics even of going in or seeing a family. It's what are we bringing into that family?

So I think there's so many questions. What I wanted to do is kind of open it up for some positive examples of some really creative ways UCEDDs and LENDs are helping their state systems reach out to find families, to help families, and then if... you know, if possible, give actual early intervention through different creative ways. This network is just so full of experts and expertise that I think it's a waste if we don't use our creative brains and collaborate about how to make things better in a situation that sometimes looks very dire and bleak.

So, anybody want to add in any questions in the chat box or going forward? I do have... I see the issue about LENDs. I will tell you where LEND hit us is that we weren't able to make family visits. So our last family projects weren't done. And because schools were really just getting up to a new remote way of learning. Many of our folks could not even participate remotely. Special ed or school psych or PT or OT schools. And some of you may or may not know, many of our licensing boards and state certification offices are waiving hours that people need in order to get credentialed. It makes perfect sense they're doing that with nurses and med students, but they're also doing it with audiologists, PTs, SLPs, social work. So that has had a direct implication on basically being able to provide some extra support to people as they're in learning programs.

So Deana Buck, I see you typing. I will also put up there that each one of our UCEDDs has lots of information, both across the lifespan, and we shared those on the UCEDD director meetings. So everybody please go to the different UCEDDs and there's lots of resources up for every -- every UCEDD has a COVID page and every program usually has a COVID page. I would also mention that for early childhood intervention, ECTA is the COVID center. ECPCTA also has personnel information specific to COVID.

But can we hear some direct, very specific areas before we can start jumping in? Maureen and I have some things we have heard that are just wonderful. But other people? More questions for Maureen, please. She's our expert here.

>> MAUREEN GREER: Mary Beth, while waiting for that, one of the things I would encourage people to think about is the new reports that are coming out for very vulnerable high risk families. The incidence of domestic violence is going up. And so you have very young children in unsafe areas and all of this staying at home is exacerbating that.

So be aware that sometimes a family may just need a phone call to check in and say how are you doing, is everything okay? It isn't always the therapy that is important. It's the human connection. And I think sometimes we get so focused on delivering therapy that we forget to listen and listen for not only what is said but what isn't said, the undercurrents that exist. And in these times it's really important to do that.

>> MARY BETH BRUDER: Thank you. I don't know why -- somebody typed in they hear two people speaking. If people have their speakers on, if you could just make sure, you know, you muted yourself. I agreed and I think that what you pointed out, is the most important skill in my estimation is that early childhood intervention has, which is listening. It really needs to be first and foremost in any kind of interactions we have with families, no matter when we're having them but now even more importantly.

>> MAUREEN GREER: There's a question around recommendations for technology access to families in rural areas without Internet capabilities. What we have heard from some of the states or what they're hearing from local providers is buying hotspots for families that may have a phone but not have good WiFi access. That seems to be working to a certain extent. But the real reality is that it's a real -- it is a challenge to figure out how to serve those. And that's what is creating this inequity. I think following some of the examples of school systems where they are dealing with that by creating learning packets, etc. Early intervention can do that to a certain extent, you know, sending a sheet with here are some things you might want to consider doing, or looking at are there books to read, childhood books that you can send and Mom or Dad could read to that toddler.

But it does create a level of -- it requires a level of creativity but it also, again, like so many things that has been pointed out to us during this pandemic that we have real inequities in our society and this crisis has just focused a spotlight on them, and quite honestly there aren't good answers for everything. There are literally going to be families that short of a telephone, we may not be able to do what we would like to do. It just is part of the reality that the country is facing.

>> MARY BETH BRUDER: One of the other things -- I'll try to get to everybody putting great things up, but I just heard this. And Larry, you put this in. I don't know what state you're in. Can you put that down? That districts are sending school buses out to provide hotspots for virtual connections for families. I have heard of that too. And in rural areas in particular. And that is just -- when I heard that, I thought that was the best idea I had heard that day. It just really helps families. So it's in Arizona also. And I think that that's definitely one of those creative things. Elizabeth Morgan, you are at UC Davis and you are having virtual cafes. And you're also doing several things for providers and teachers. Any one of you, just, again, if you want to put your contact information so people can reach out and get them, they're moving so

fast. There's curriculum modules. There's also... and that's from Alicia. And there's lots of other things going out here.

>> MAUREEN GREER: Deanna had a good one, some providers are going to a family's driveway and using their hotspot so the family was able to connect.

>> MARY BETH BRUDER: That's a great idea. Phone visits and mailing information, yes. Telephone sessions.

>> MAUREEN GREER: A little bit of a challenge around telephone sessions, Mary Beth, is that some states Medicaid will not pay for the telephone consultation because there's no eyes on. It's simply a voice. So if a state has funding to support that, that is not Medicaid related, then they may be doing that as well.

>> MARY BETH BRUDER: And Deanna, local administrators meeting twice to. I think that is having people have their own support. And I think our teachers and early interventionists also need to make sure they're connected to their own peers as they try to meet the needs of families.

So are there any supports for school-age physical therapy providers? I don't want to call a Toby Long, but I saw she's on here. Toby, are there supports you can write in? I saw Tricia is also on here. So I know there's a couple of PTs.

So one of the questions, while they're typing about PT... oh, here is families who sent video.

Families who are saying "no" to services right now, are there any policies and procedures that people say that everybody gets at least a once a week phone call just for the welfare, wellbeing check? Or are families just saying, I'll call you when this is all over? That's out of curiosity I'm asking that question to see how families are communicating what they want and what plans or ideas people have to not let them get that far out of the loop.

>> MAUREEN GREER: Mary Beth, some states are reporting that families are declining services right now, that they just can't handle anything more and they'll get back in touch when things settle done.

>> MARY BETH BRUDER: Right. And I keep seeing that two people are talking at once. I think you're getting an echo. Because we're not talking at once, unless somebody else is. So we apologize again for this audio.

>> MAUREEN GREER: Somebody is asking if there is a secure platform for families to send videos?

I'm going to go back to the questions of the parents who said don't contact me until COVID-19 is over. And as Maureen said, most of us realize we're in for a long haul at the very worst case scenario, it's going to be a minimum of 12 more months. The best case, we all get out of our

houses a little bit over the summer until the flu season starts. What are people going to be doing if families say not until the end will we be checking in?

Some people are saying now that it's a longer time period, families aren't checking in.

And there are people doing that. Toby Long, you're going fast. If you are on, chime in with a link to your info.

I feel like I'm on Prayer Home Companion and saying, so and so, somebody is asking you to call.

So in Vermont, PTs, OTs in the UCEDD are hosting open forum remote meetings for OTs and PTs across the state. What a great idea.

The same for EI providers. Absolutely great way to share the best way to do it in your state.

Kathy, you're telling us Internet and cell providers have opened up hotspots free, but it's a challenge for families who aren't native English speakers.

So I'm curious, as with Morgan, some of the families, one of the parents... waited, I just went past real fast. Having providers come in wearing protective gear. We do know that in the northeast. Some ABA providers are going into families' homes to do ABA intervention. And wash their hands. Again, I think that's an ethical call and it's also a public health call in some states. And I think that that's something we being in the helping profession need to be very wide open about in terms of weighing the benefits versus the risks.

>> MAUREEN GREER: On both sides, both for the families and child but also for the provider community as well. Because they go home at night to families as well.

>> MARY BETH BRUDER: Yes. So PPT, School SIG is having a region tall town hall meetings and they have been helpful. Davidson, is there a link you can put in here for PTs who want to get into that? And PT in Maine, continue to check in with families on a regular schedule without expectations for them to get back to us.

So people want to get a link to that town hall if they can.

I have a switch of a question. Keep coming with these.

For any UCEDDs that are actually directly providing services, have you moved totally to telehealth, and how about for evaluation clinics in particular, what has been going on?

So Kati Ringer Vermont Childrens integrated services is providing services through telehealth and webinars.

So regional representatives for the school-based SIG for APPT.

So it's pediatric PT.org. You have to be a member to attend live. But the recording should be posted. Okay. So there's a lot of information up there for PTs now. Thank you all so much.

So here we have in New York some children who are mandated for family training sessions with the whole team one time a month. They're not occurring, although their individual sessions are approved. This type of service is provided to our most at risk children whose parents need this for problem solving establishing goals and negotiating the system. Informally we do it. Any other ideas?

Thank you for the hot links you guys.

And Affirm has very useful resources. I second that. Wonderful videos and materials for kids on the spectrum.

>> MAUREEN GREER: You know, Mary Beth, one of the things I'm thinking about as I'm listening to all these wonderful resources is are the UCEDD programs and LEND programs giving this to their Part C lead agency so that they can share that information with their providers? How do we make sure the communication about all of these resources are spread widely in your state so that we reach sort of all corners of the state and make sure that providers have the information they do? It's great you're sharing them among yourselves right here, but how are you sharing that with your state system as well as your provider networks in your state?

>> MARY BETH BRUDER: Thank you, Elizabeth Morgan, for research to practice, which is always the best way to get practice out there with a link for anybody to do that.

I agree, Maureen, and I would give a challenge to everybody here that if you do not know what is happening if your state, policy or practice, that you do outreach to them. I think we're a little past the crisis mode where everybody was reacting as fast as they can and changing practice. This has been the fastest systems change that I ever witnessed in regard to taking one service delivery model and changing it, it seemed like overnight. I know in Connecticut, our wonderful people did do it almost overnight. And I think in every other state people have been asked to change their roles incredibly fast. And to take on a new persona if you will, and to learn technology, which also can be challenging. And then to help families feel comfortable with technology.

So we have done a huge amount of change in the past not quite even two months. About six weeks. And I think we need to pat our service providers and service systems on the back for doing that. And I think our next challenge is really to find out how to engage families, especially those families looking at those slides Maureen had, which are very sobering, but very real. Figuring out how we outreach to families in a way that they are comfortable and able to focus on what we can offer them. And in the meantime find out what they want us to offer them and do that.

We are in this for a little while longer, to say it nicely, and I take Maureen's challenge, are we ever going to go back to different ways?

I know, for example, preschool teachers who never really had an opportunity to spend much time with families are now in that role and are enjoying it and recognizing that what happens in the home is just as important if not more so than what happens in the classroom. We always have known that at birth to three, that we're only there for a little bitty time, but what we can do in the future is how -- let's look at families and maybe family engagement will have the spotlight it should always have had, which is different ways for different families.

So looking back, there's more hot topics. And Maine APTA, telehealth, thank you, Toby, for your links and sharing information.

I had told everybody that we would end at 4:00 since John was not able to join us. So Maureen, are there any last words you have? I think that -- I thank you all for participating this way and putting these resources up. And Anna, these will be posted. I'm wondering if we can just export. We do have some more people typing.

[echoing]

Somebody has their line open. Sorry [echoing]...

Maureen, do you have any last words here?

>> MAUREEN GREER: A tremendous thank you to all of you who are working so hard to provide either the direct service themselves or support the people who are. Your experience and expertise are more important than ever. Please make sure you connect with your Part C system, give them the links that you're all discussing, and see how you can be involved in that planning as we move forward for whatever our new reality is going to be, but we have a wonderful community of varied perspectives, and we're lucky to be part of that community.

>> MARY BETH BRUDER: We are. I have never felt more proud of our field than I have watching what has happened from the ground up, for service providers who are doing their best to manage their own families and their own families' learning at home and still remembering what their -- not just their job, but for most of us it is a vocation. And also for our state systems who have been right there stepping up and supporting the practitioners. And UCEDDs and LENDs who are always there. And as I started out, we want to make sure that we celebrate the collaborations we can do, and make this a learning opportunity. Because, you know, the famous saying "Never waste a crisis." This is a chance for us to learn about ourselves, our field and most importantly how we can better serve children and families.

So thank you all for spending the hour with us. Two weeks from now we'll have John. And let me just do another little preview, because I see my good friend and colleague Ann Turnbull is on. Ann will join us on the 19th with Darla and Molly where we will be going over the results of a survey that we did for families. Some of you sent it out for us. We sent it through UCEDDs and LENDs, and Part C and 619 and we have 1100 responses from families around the country telling us what life is like and what life is like for their child who has disabilities, delays or special needs. We will share that on May 19th, 3:00 to 4:30 and we invite you to that. I look

forward to that and having a discussion with these wonderful family leaders. Thank you all and stay healthy and stay safe.

>> Thank you, Mary Beth. Thank you, Maureen. Thank you everyone for joining. Sorry for the technical difficulties. We're going to move probably to a different platform in two weeks. Keep an eye out. Probably will be on Zoom. I will take the chat box and flesh out the resources and we'll send it out to the registrants probably sometime this week. Thank you again for attending. There's going to be a short little survey when we close out, please take a moment to fill it out. Thanks again, everyone. Be well.

>> Thank you, Anna.