

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES (AUCD)
NETWORK PUBLIC HEALTH WEBINAR SERIES ON COVID-19 – SESSION 2: ADVICE FROM FAMILY
MEMBERS AND CAREGIVERS ON DEALING WITH COVID-19

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Remote CART Captioning

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This transcript is being provided in rough-draft format.



>> Hello? Can anyone hear me?

>> Yes.

>> Hello, everyone, and welcome to the AUCD network webinar series on people with disabilities and COVID-19. Today is the second of four webinars. Today's webinar will provide advice from family members and caregivers. My name is Ilka Riddle and I'm an associate professor at the University of Cincinnati and Cincinnati Children's Hospital. I'm also the director of the University of Cincinnati Center for Excellence in Developmental Disabilities. In addition, I'm the chair of AUCD disability and health special interest group. Together with Dr. Adriane Griffen, senior director of public health and leadership at AUCD, I'm one of the facilitators of this webinar.

First, we would like to thank all of you for joining us today. We know that serve very busy with working from home, schooling at home and taking care of loved ones in these rather challenging times. Before we begin with the actual presentations, I would like to address a few logistical details.

Because of the large number of participants, your audio lines will be muted throughout the webinar. However, you can submit your questions at any point during the presentation or after all presentations have concluded via the chatbox on your screen. You may send a question or comment in the chatbox to the whole audience or privately to the staff or presenters. We will compile your questions throughout the

webinar and address them at the end via our discussant and our Q and A marshal. Please note that we may not be able to address every question and we may have to combine some of your questions.

The webinar is being captioned and ASL interpretation is provided. This webinar is also being recorded and will be available on AUCD's webinar library. There will be an evaluation survey at close of the webinar. We invite you to provide feedback on the webinar and provide suggestions for future topics.

So, why are we doing this webinar series? Over the last few weeks, we have learned quickly that the needs of people with disabilities and their families during the coronavirus pandemic are not well-addressed. And we decided that information from experts in our field of developmental disabilities could be helpful to all of us. Therefore, we created this webinar series with the hope that you will find the information useful.

Now, I would like to welcome today's distinguished panel of speakers and thank them very much for agreeing to present today. All of them are family caregivers themselves or support family caregivers and we feel very fortunate that they are with us today. Our panelists today include Dr. Joni Beasley from the Center for START Services at Institute on Disabilities which is the UCEDD at the University of New Hampshire. Dr. Iowa a, assistant professor and associate director of the University of Cincinnati UCEDD who is also a parent and a person with a disability. Miss Celia Schloemer who is the family support coordinator at the University of Cincinnati UCEDD and also a parent. Dr. Carol Salas Pagan who is the director of the UCEDD in Puerto Rico and who serves on the AU CD board. And Miss Benita Shaw who is the UC Davis MIND Institute resource center and who is the founder of GIFTS Foundation. She's also a family advocate and member of the board for the supportive life institute and the library foundation. She's also a parent of two young men. One who has a disability.

In addition to our fantastic speakers, we also invited a wonderful great discussant and our question and answer marshal. Miss Fran Goldfarb, the chair of the LEND family network for the California LEND program. And Mr. David Deere who recently retired

from the Arkansas UCEDD and LEND program. And who is the current volunteer codirector for the specialty diagnosis resource center. And in charge of the fetal alcohol disorders special interest group at AUCD.

The panel will speak first followed by remarks and thoughts from our discussants. And then marshal will lead us through the audience questions. I will now pass it on to Dr. Adriane Griffen who will get us started with a few words about public health. Thank you.

>> Adriane Griffen: Thank you, Dr. Riddle. And welcome, everyone. We appreciate your taking the time to join us today. Before we get started, we got quite a few questions from our different constituents across the country on what exactly is "Public health"? So, I just wanted to take a minute to share how we think about public health at the National Center on disability and public health. We really have looked at it really holistically. Looking at how public health really enhances your health of how you live, work and play in the community as well as where you, you know, might be able to adopt healthier behaviors. How you can increase your actions in your daily life to make sure that you are doing what you can to be healthy and well.

We also recognize that it's a blend of science as well as an art to help you live well and prevent disease and that it takes place through an organized effort. We also for how we define it in terms of the National Center on Disability and Public Health, we see it as something that belongs to everyone. That public health is indeed for everyone. Public health is a way to share tools for managing change, such as COVID-19, and really think creatively about doing things differently. With that said, I wanted to let you share in that framework so that you see how we are thinking about public health as we look forward to hearing from all of our speakers today on their strategies on thinking creatively and doing things differently among our changes with COVID-19.

So, it is my pleasure to turn the virtual stage over to Dr. Joni Beasley who is going to give us an opening.

>> Joni Beasley: Also, the sibling of a person with intellectual disabilities.

>> Dr. Beasley, I'm sorry, I wasn't able to hear you in the beginning. Are you able to start again?

>> Joni Beasley: Yes. Can you hear me now?

>> Yes.

>> Joni Beasley: Can you hear me?

>> Yes, now we can.

>> Joni Beasley: Hi, I'm Joni Beasley. Center for START Services, and part of the special interest group at UCEDD. And the sister of a person with intellectual disabilities. My oldest sister, Susan, who is a very valuable and important person in my life. And what I'm going to do is start us out with a brief meditation. It's the form of meditation that we use is called insight meditation. And there's a lot of information about insight meditation. And I would look up Sharon Salzberg. And I would send the reference to all of you, to AUCD so they can share it with all of you.

And what I would like you to do -- could that person be muted, please? I would like to ask you all to sit quietly for a few minutes and follow this direction. The idea of insight meditation is that it seems very welcoming for you and very easily accessible to you. To give you an opportunity to have positive thoughts and hopes. Every challenge that we face in life is a challenge that can be addressed if we can have hope. And the way we have hope is by using strength-based approaches and really being in touch with our own ability to be happy and healthy through these approaches.

And so, we're going to practice actually using those words. The meditation will take you into four stages. So, the first thing I want you to do is notice your breath. I don't want you to struggle with it or practice different kinds of breathing. We're all breathing. So, just notice that you're breathing. And really try to focus on that. And while you're noticing that you're breathing, I'm going to walk you through a simple insight meditation that I have found helpful and that we have used with people with disabilities across the United States and their families.

The first thing I would like you to do is have a wish for yourself. So, I would like you to either close your eyes or look straight ahead. And I would like the person who is interpreting to do this really sort of

gently and in a mellow way so that the person can really feel the vibe of a meditation. And what I'd like you to do is to say to yourself a wish. And I would like you to wish for yourself to be happy and healthy. I wish to be happy and healthy.

And I would like you to take few seconds to do that. Just think this for yourself. Wish this for yourself. I wish to be happy and healthy.

Now, I would like you to think about somebody that you love very much. Somebody who you really have this wish for. I wish for this person to be happy and healthy. Don't forget to breathe. Don't forget that you're breathing. I wish this person I love to be happy and healthy.

Now I would like you to think about somebody who you don't know very well. Somebody that you might see. Maybe it's the person who delivered your groceries. Maybe it's the postal person who delivered your mail. Maybe it's somebody -- maybe it's the interpreter on the screen in front of you. But I would like you to share that wish with that person. You may not know them well, but you wish them to be happy and healthy. I wish for this person to be happy and healthy. And one final person. I want you to think about somebody who really annoys you.

They really are aggravating you right now. It could be like your spouse, even. Somebody that's really pissing you off. And I want you to think in your mind: I wish this person to be happy and healthy. I wish for this person just to be happy and healthy.

I would like you to come back and notice your breath a little bit. Remember, you're still breathing. And think about how often -- how much time do you take wishing others to be happy and healthy? Maybe even somebody that's aggravating you. But how much time do you dedicate to that first wish? That first intention for yourself to be happy and healthy? It's a very, very important part of overcoming the obstacles that we face and having the resilience and the hope for future.

So, I'm gonna leave you with a final wish. And -- and one other thing I just want to mention before I give you my final wish. And that is: We feel what we feel. We feel what we feel. So, those of us who feel anxious, those of us who feel worried and upset. We feel what we feel. It's okay. It doesn't

undermine your ability to wish that you're happy and healthy. Which is one reason why I think this meditative practice is so powerful. So, in a loving kindness practice, like the one that I just shared with you, I am going to leave you with four final wishes for you. May you be safe. May you be happy. May you be healthy. And may you live with ease.

I want to thank you for this opportunity to share a few moments with you. And enjoy the rest of the discussion today. Thank you.

>> Ilka Riddle: Thank you, Dr. Beasley. That was beautiful. Next up we will have Dr. Kara Ayers who will share with us the lived experience of being a parent and caregiver and spouse and professional. All the hats you wear. Dr. Ayers, take it away.

>> Dr. Ayers: Thank you so much, Dr. Beasley. I feel fortunate that I got to take part in that before speaking. Thank you. I just wanted to quickly list some of the organizations that I'm a part of and hope that you can connect with us after this webinar. They -- especially the overlapping roles that I'm going to discuss. So, I am -- along with -- I work at the University of Cincinnati UCEDD. The director. And the co-founder of the Disabled Parenting Project. And a newly formed Center for dignity in health care for people with disabilities. I hope that you can connect with me through these projects after today's webinar as well.

This is a photo of me and my family. A couple of falls ago. And, my husband and I are both wheelchair users. And I'm often reminded of the multiple overlapping roles of caregiving. So, we both -- he often reminds me, we both have the role of caregivers for each other. And our children, we have three children. And one of our children has a disability as well.

So, I think sometimes when we think of family support, we fall into a trap of thinking about non-disabled caregivers caring for people with disabilities. And even more specifically, we spend time to think about non-disabled adult caregivers caring for children with disabilities. But we know that our families look a lot more diverse than that, a lot more complex. So, we need to step out of that rigid thinking so that we can also recognize siblings and grandparents and the needs of aging family members

and recognizing that more than one member of a household might have a disability. So, there are definite strengths to that. We know the resiliency. I look at disability from a strength-based perspective in my research as well. While there are definitely strengths, I know that it can also multiply some of the barriers faced by people with disabilities when more than one person in a home has a disability.

Especially right now, barriers to accessing care. Ways that your family might have previously gotten around, transportation, or maintained your non-COVID-19 health care needs might have totally changed. Another issue that I am faced with as a caregiver is previous supports that worked for me, that I might have even looked at as disability hacks in a way of making my life easier are now being used by lots and lots of people. So, they're overtaxed.

And so, an example of that for our family has been grocery pickup. For quite a while now as a family of five, the physical load of the number of groceries that we have has required us to use grocery pickup. But we've never been in the situation of needed to look for times more than a week out. And so, services that we have used in the past have now become popular for everyone. And, it can make it more difficult for us to get in there with our needs. I also see hope -- glimmers of hope in that we're kind of mainstreaming some previous services that people with disabilities found helpful. And we may see benefit from that down the road. I guess we have to wait and see.

I have been thinking a lot about ways to advocate as a caregiver. And this is an exciting time if you're into policy as I am. Because nearly every organization is a policy making organization right now. So, schools are making decisions about policies. Even grocery stores. You know, your doctor's office. And all of them need to hear our voices as caregivers. With respect to the fact that you have to consider your own mental health in terms of how many places your voice can be -- can be spread before it's taxing.

But I think that there are more than enough opportunities to let people know from a caregiver perspective how these policies can help -- be helpful for us. And there are formal ways and there are also less formal ways. Letting your school or your grocery

store know your shopping needs can hopefully align the proposals more with what we needed a family members.

But also, I wanted you to keep in mind some keywords in your advocacy. And I would narrow them down to medical discrimination. You may have heard of that along with the talk of rationing of care now as hospital systems become -- or overreach their capacity. There have been some pretty scary discussions around rationing of care. And the term "Medical discrimination" really means that people with disabilities are not given the same access to the same quality of treatment based on their disability alone.

So, whether it's COVID-19-related or not, that's something that as a caregiver I watch for always, but especially right now. Another term that I know we have in our toolbox, but I want to apply to our situation right now is reasonable accommodation. I'm specifically thinking of some of the blanket visitor bans in hospitals. A way that you can apply federal law to discuss exceptions to this. And we're seeing more policy help and support in your argument as a caregiver. But if you're in a situation where you need to accompany a family member who has a disability, it's a reasonable accommodation. You can explain it in that framework. It kind of help use connect your explanation as a family member to the law that protects your rights.

And just another quick example of ways that I'm seeing that our voices as family members are being heard is you may have heard just Monday night, Social Security Administration has released new guidance for mostly parents with -- who receive Social Security benefits. Parents with disabilities who also have dependents can now file for stimulus dependants related to those dependents. So, it's little things like this that we're helping to have in this example Social Security recognize that there are also parents with disabilities who receive Social Security and also have dependents.

So, we're making our voices heard in big ways, in small ways. You know, and I think we are hopefully seeing both points we need to work on and also some glimmers of successes that we can highlight. An example for that I would touch on quickly would be many of us, myself included, are

making our way through distance learning with kids at home. And we're hearing important examples of how this needs to be made more accessible. But we're also hearing from, especially members on the Hill, that we need to hear a story where it is working so that we can spread those success stories. I know AUCD is collecting those right now. A quick plug of looking at, you know, multiple sides of an argument at once.

And in this case, the argument is, is distance learning working? And my argument is always that if it's working for students with disabilities -- without disabilities -- we need to figure out how to make it work for students without. So, trying to look for both the struggles and the successes is important.

Also, I hope you are also already starting to take note of the lessons we're learning. They're coming at a rapid pace. So, the urgency of future planning. And there's been a lot of anxiety around that for me as a caregiver, recognizing that some of the plans that I thought I had in place don't make a lot of sense with the new landscape. Especially with so many changes at once.

I hope that as family members we are recognizing the really frightening risks of congregant living hearing from media reports. But even more worrisome is we're not hearing those stories because of the isolation and nursing homes and developmental centers and group homes are under right now. So, just as another note of lessons that we're learning as we go, we're seeing that the caregiver crisis is being exacerbated. But perhaps a glimmer of hope in that we're seeing how fast some adjustments can be made in some states. So, we should take note that have.

And also, just this ongoing need but even more so now for disability and family representation on ethics committees and in medical systems. So, when we see these calls for family and patient advisory councils, I think never more have we been given examples through this pandemic as to how it can make life or death differences in policy making.

And last on this is notes of lessons learned is just changes to service delivery that would be helpful to maintain. So, right now a lot of us are wondering, you know, how much longer? And when will things

change sort of back to our new normal? And we don't want to lose track of what's worked and kind of lose that as we move back to a new normal. So, I feel like the cat's kind of out of the bag on what has worked. And this is going to vary family-to-family. What worked for me might not work for you.

So, the rapid transition to working from home has been something that for many people with disabilities has been something they've asked for in the past but have been told wasn't possible. Now we see that in many industries that is possible. This increased public knowledge on health behaviors I think has been fascinating to watch. Before, you know, we moved to schooling at distance, schools were integrate it in their curriculum. It's interesting to see how that will continue. Also, related to social distancing and as a caregiver, I know one of my concerns has been that just the visible nature of our disabilities in public can cause people to come up to us and not respect social distancing.

So, striking that balance between educating the public of the need for everyone to have social distance while also not inadvertently sending a message of, you know, stay away from my family. We have disabilities. That's not the message I want to send. But I want to make sure that my family can be safe as I take them out in public in the future. Telehealth, we have worked with that, is important to keep going, build upon.

And the online dissemination of adaptive exercise programs is very exciting to see and see where that goes from here. My last point on where we go from here is that, oh, one final on the last slide is just taking note that some of those policy changes are made permanent. I was excited to see that the policy change of allowing some direct support professionals to accompany people in the hospital is actually not time limited. That was in one of the first COVID-19 packages, policy packages. Taking note of what's permanent and what's not for caregivers and our advocacy efforts.

And as we transition, one of the urgent concerns I have, this question of we heard the tagline, we're in this together. But I worry that, you know, are we still in this together? We need to pay attention to language from policy makers. Even well-intentioned

that describe families like mine as the vulnerable folks.

I worry that it's really othering our families from I guess non-- less vulnerable populations. I won't even say non-vulnerable. The personal decisions among family members about how and when we quote, unquote, return to our new normal are going to vary. And I have concerns about whether these supports for sheltering in place for social distance that are in place right now. Because the masses need them, are going to remain for families that do have higher risk, especially if we contract COVID-19. But in truth, we're learning from this virus that none of us are without danger. I hope that we keep that slogan, we are in this together in mind and don't separate ourselves as we transition to our new normal. Thank you for the opportunity to speak today and I look forward to your questions.

>> Ilka Riddle: Thank you, Dr. Ayers. That was wonderful. Next up, we will hear from Celia Schloemer. Sharing some practical tips just for dealing with COVID-19 and other strategies for family support.

>> Celia Schloemer: Thank you. It's such a privilege to be here. I want to share as the family support coordinator at the UCEDD, I come to this position from what I consider a place of privilege. Of not only being a parent, but also being a sibling, a sister-in-law and an aunt to individuals with disabilities. I've learned a lot across the way and just really am passionate about sharing and having that family lens as we look at this. So, I really wanted to have the focus of my time with you to be about practical ways and help connect you to things that are available now that, you know, even as soon as a week ago were not available that can help families on this journey as we all kind of figure this out.

And so, I think the first thing that's important is to recognize that we have families of individuals with disabilities are resilient. We say that a lot. But I have seen that resiliency shine as the face of the challenges that we're facing now are new to families. Currently families of individuals with disabilities come with a bag of tools and personal experiences that's going to help them through this.

But I think it's important to recognize right now

to whenever they can I'm encouraging families to find that space of optimism. Finding that one win of the day and recognizing that we all are running into places that the day doesn't turn out the way we had planned. Or the plan isn't coming to fruition. But if we can keep those places and spaces looking at the end of the day and say what was the win is super-important. I think just kind of having that margin of forgiveness. Knowing that each day is like a dry erase board and we have the opportunity for a do over the next day and kind of reestablishing our resiliency to a space that we can take on the next day is really important with families.

And that we're not alone. And that we're all kind of doing this. And this is -- it's kind of nice. We have a much bigger crowd to lean on, to talk to about these daily struggles or challenges that we're facing. So, that's important. Whoops. My slides are moving on their own. Okay. So -- so, knowing very quickly, I tried to find little tidbits of advice to help families focus. And I think the first thing is to help them recognize the small locus of control. And recognize -- we can't control everything. But we can find little things that we know will be successful.

For me, we were joking in another setting that mine is laundry. If I can maintain laundry, I'm going to be okay. If I can know at the end of the day that thing isn't getting bigger and bigger and the mountain isn't taller, that's a success point, a win. Praising each other's strengths. I have not been in a time when I am seeing more of even colleagues that were expressing appreciation kind of saying great job more often than we ever do. And I think that within families during these times that are difficult, recognizing those places and doing that for family members can change the economics of a household pretty quickly. But I think because we're in these spaces that are work spaces and family spaces and we've got to somehow find our own personal spaces to have the quiet time that we were encouraged to have earlier. We've really got to create a specific space for family time and honor that time.

And not have it be about a to do list or a discussion. But have it be about listening and hearing each other's voices and understanding each other's struggles. And again, bringing those times

back to that point of optimism. When we talk about phase of control. Control can be a slippery slope. We want to be really cautious. But the phrase I heard that stood out was the idea of unanticipated opportunity. And so, it may not be the way I planned for it to turn out. It may not be in my control. But there's been an opportunity for growth. There's been an opportunity for a new level or a new type of support that wasn't there before. And taking advantage of those and note of those and recognizing that those two are places that we can feel a win.

Having a plan is -- is really -- can be instrumental to give us a little more sense of ease and reduce our stress and give us that feeling of some level of control. And we all can -- we all respond to a plan differently. It can be something as simple as a -- a list, a checklist. It can be something for complex. But always having some sense of what your day might unfold to look like can help families relax and know at the end that they've accomplished something.

Also, the plan itself. I think right now a care plan, you know, is something that's really important. Kara shared that many of us had what we thought was a care plan and it's not fitting to these times. Or in fact we've always said, I've got to get that taken care of and we haven't done it. So, important to consider a plan not only for your most vulnerable family member, but for what if you get sick? And having that plan unfold for each family member. Recognizing who is going to be the primary caregiver for any one given family member if they were to get sick?

We actually in our family ended up having an individual in our household that tested positive. Things like how you gonna set up and use bathrooms? How are you gonna arrange sleeping? Having kind of thought through those things at least a little bit, expecting that they will change. But it's amazing to me what that can do. And we're at such a great time right now that lots and lots of information is being disseminated. Products are being created to make this easier on families. And at the end of my slides, I've included a slide that has links for some of the things I'm sharing today. But the University of Southern Florida had a great piece, a health passport.

It's a four-page document. Which it can be kind of cumbersome, but it's graphically very easy to understand and follow. And it goes a little deeper and really talks about what it takes to support this individual beyond medical information and provider information. But, you know, what's important in my eating routine? What's important in my sleeping routine? Things that really are gonna make or break a family member who may be in a new setting where they don't know them as well.

The Stony Brook University did a fillable form. More like a medical form. But because you can type directly into it, it can be done relatively quickly and printed off. I encourage you to encourage families if you're a professional or a family member yourself. Have several copies available. It's silly to say laminate it now. I'm not sure everyone has the laminating opportunity at home. But also, just choose a sturdier paper thinking this may go into a different setting and make sure it can be utilized and withstand that more frequent use.

In addition, I shared hear some of the work that's coming out of UMKC, the University of Missouri-Kansas City, around the charting the life coursework. There's some great very basic simple tools that are person-centered around supports and important information to be shared about an individual. And these are great tools. And they're nice because they're simple and many of our family members have utilized these and filled them out themselves. So, they're familiar. Those are great opportunities to use at this time.

Remember that we're all just learning how to do this. I think giving yourself space to learn. Also giving those that you're working with. I think that's one thing in my family support role, especially around education. There's -- there's a real balance to understanding that teachers, administrators, student services groups, are doing this for the first time. And we're all learning. But I think the most important part of that is keeping the conversation going.

And making sure that in those spaces the conversations are about what you can do and not necessarily focusing on what you can't. We're often focusing on that. And we need to flip that switch so that we are having positive conversations that can

move us forward. It's important to take it one step at a time and be forgiving with yourself to know if that step didn't work that you can turn it around and try something new. And, again, talking to each other and we have been so good about disseminating information. But we want to make sure that we're making those connections with others and talking about what worked for them and sharing ideas.

And I've seen us as a field really take off with that and making sure that we're disseminating and sharing every possible thing that we've come across that we feel like might be helpful. Also, identifying what's good enough. I think that can really slow things down and give families breathing room. It's not about doing it perfectly the first time or making sure that we're doing exactly what school wants and exactly what work wants and exactly what our toddler wants. Really stopping and going, what is good enough? What can I maintain and still have my own mental health at a point where I can get up and manage the next day?

And really recognizing what your tipping point is. What is it that just can't happen for you to be able to move forward? And breathing through those spaces, and planning through those spaces so that you're prepared. And the last two points remind me, again, going back to simple ideas to track it, of a piece from charting the life course that gives us this trajectory of what we want versus what we don't want. And looking at those spaces and uses these tools to just simply, what is it that I have to be able to do today? And what can I not have happen to get through the next day? And these are great graphic organizers that help you place those ideas on paper.

And lastly, one of the things we have to think about is the idea of a routine. And you hear it spoken of a lot these days of building in a routine, helping your family know what to expect from one moment to the next. And these are beautiful. But we've got to find that sweet spot. Because we're kind of all managing our own personal priorities. And every family member's different. And every family's need for or sweet spot for a routine is different. So, making room for all of those and valuing every -- everyone's needs and approaches to this is super-important to remind families. We need to be

flexible. We need to change and accommodate. And I think as parents, especially in this group, we need to be flexible with ourselves. And focus on -- on what it is that's doable. And then lastly, I think we need to encourage -- we talked a lot about independence in this field.

And I think encouraging -- this is a great time to not only focus on the places where we can see be independent in these spaces that we're kind of quarantined in. But it's important to recognize, this is a great time to work on interdependence and talking about where each individual within the family's value is. And helping that reciprocal relationship and that reciprocity of I'm valued, and you're valued come up and bubble up in places that sometimes we don't have time to create when we're in our far more typical day-to-day lives. This last slide has lots of links to refer back to and see the spaces. I have included our website, we have the charting the life course. That community has done such a great job in sharing and I've placed a lot of those pieces on that page where people are uses examples of how they used this.

I've -- I also included a place where you can help create a visual schedule if that works better for some of the folks that you're spending time with. With free pictures for things like that. And also, the health passport and those things also. So, the last thing I want to offer is I don't think this is just what Justice Brandeis meant, but I think it applies. Sunlight is the best disinfectant. And I think right now stepping outside of your house and feeling the sun in your face, number one, is a huge game changer for me and I recommend it for everyone.

And the second one is the idea of shining a positive light on things. And that sunny disposition that my mother always spoke about is another way to just kind of squash the negativity and the difficult, challenging spaces that we're experiencing right now. So, thank you for your time and I look forward to your questions.

>> Ilka Riddle: Thank you so much. We really appreciate your remarks and tips. Yeah. Getting outside. It does wonders. Next up we will hear from Dr. Carol Salas. Puerto Rico's UCEDD and talk about current actions they're taking and offer some

advice.

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>> Carol Salas Pagan: Can you hear me well?

>> Ilka Riddle: Yes.

>> Carol Salas Pagan: Thank you. It's an honor. Good afternoon to everyone. As Ilka said, I'm the Puerto Rico UCEDD director and the Puerto Rico family to family center director. Part of the AUCD board and also a member of the FEMA National Advisory Council. So, I just want to talk a bit about the perspective of what is going on with the COVID-19 in terms of people with disabilities in Puerto Rico. So, our UCEDD is part of the public health school in the Medical Science Campus of the University of Puerto Rico.

So, gladly, the government and the current governor of Puerto Rico asked our University to comprise -- compose a task force -- a medical task force -- composed of all the deans and our chancellors to help and advise the government in how to respond to these new virus and pandemic. So, since day one, the task force was created a UCEDD director was able to have direct communication. And the first thing I wanted to make sure to raise the alarm about the threat that this virus will pose to people with disabilities. And for people with chronic health conditions.

Because we know that our communities are at risk -- greater risk with the new virus. So, one of the things that I was advocating for was -- and the message I was trying to give to all the -- to the task -- medical task force -- was that it is essential that people with disabilities and their families were ensured that their health was a priority that they needed to be present, include and the informed about all this new information. And as all the presenters previously have said about the changes and rapid changes of these conditions.

So, what do we do and what we are doing? The current actions that we are taking here to make sure people with disabilities are -- and their families -- are present, included and informed. So, one thing we learned after Maria, the Hurricane Maria hit Puerto Rico, is that emergency preparedness is -- the collaboration is a special and important part

of emergency preparedness.

So, what we have been doing is the best thing we could do. It's try to collaborate, especially in this translation of diverse materials to Spanish to make sure not only Puerto Ricans in the island are aware of what's happening, but also all the other Spanish-speaking population across our nation being informed about how they can protect themselves from this virus.

So, for example, one of the materials that we translated to Spanish was the resource and technical assistance COVID-19 info booklet by and for people with disabilities. And I think some of you have already read it. And it has been disseminated in different ways in English and in Spanish.

The other thing we have been advocating for is that all the information our task force, medical task force, published would be in an accessible and in plain language so our family members and people with disabilities in Puerto Rico can be included, again, informed and take care of themselves. So, since we have been -- reaching out to the medical task force people, one of the things they asked us was to develop a protocol for the testing of COVID-19 for people with disabilities. So, this is something we're very proud of. It still hasn't been published.

But we were advocating that for the testing of people with disabilities, that they were taken into consideration are the conditions that the people with disabilities had. And also, that they could not wait long, that sometimes they won't be able to get to the laboratories to do their testing. So, what we are -- we us in the protocol was that people with disabilities were not only testing only them, but also their family members and the caregivers. And that they were given special attention for them when they needed to have that testing done.

So, right now the protocol was already approved by the State health Department. But it hasn't been published because some of the permissions from some of the private health insurance, they have been negotiating how would they be able to do the testing at the -- for the whole family members? So, that is still being negotiated. But I think it's going to be approved and disseminated very soon. So, the other thing is that we have kept

all our family-to-family centers services to cell phones and emails. Giving support to family members and to people with disabilities.

We have been -- continue giving different webinars and different spaces for families to connect and people with disabilities to connect and talk about different topics that they have interests on. And also, I've -- after Hurricane Maria, as I said before, and the response that we experienced for people with disabilities, we have been very present in trying to collaborate in establishing the Core Advisory Group. This is a group created of different nonprofit and organizations that give services to people with disabilities. And we have biweekly calls on how to respond to this, sharing information, trying to coordinate services.

They have been -- we have been disseminating information. We have been receiving feedback on the protocol that the UCEDD developed for people with disabilities. As I said before, collaboration has -- has been our keyword in trying to keep our people with disabilities here in the island healthy and connected and informed.

So, in terms of recommendations, what can I hear when we have been advocating for and telling people is that trying to -- please try to take -- stay connected with your support networks. Stay in touch with your support network. Virtually or by phone. Try to filter the information you read, and you receive. Try to share information that is evidence-based. Also, as all the other speakers said, it's very important to establish a daily routine that is real to your time right now. That -- an organized time. And rest. Don't fall into this productivity trap trying to do -- take one task at a day, one task at a time. Don't rush yourself. Make room for some activities for yourself. Breathe. Practice meditation and listen to your body, right? Connect with what your body needs. Normalize what you feel. It's allowed to feel different emotions at this moment. Explore your internal resources. Ask yourself, how have you overcome difficulties before? How have you been able to overcome other events? And make sure to keep those ideas and for you to keep them present and practice them at this moment.

Also, take this opportunity to create positive

memories within this adversity that we are all living. These are some of the messages I have from our family meetings that we tried to hold weekly through the family-to-family center and from staying connected with other advocates here in the island. And so, I'm really thankful for this time. I will be looking forward to your questions. Thank you.

>> Ilka Riddle: Thank you, Carol. That was wonderful. Next we're going to hear from Benita Shaw. Joining us from UC Davis, the MIND Institute. She's the community education specialist and has the lived experience of being the mother of two wonderful sons. Benita, I'll let you take the virtual stage.

>> Benita Shaw: Hello, everyone. Can you all hear me?

>> Ilka Riddle: Loud and clear.

>> Benita Shaw: Thank you. I'm grateful for this opportunity to be able to speak to you all today. As it was stated, I am a single mother of two amazing boys. My oldest is in college and my youngest is diagnosed with autism. Society says he is moderate to severe and he is considered non-verbal. I like to use his language is body -- first language is body language. Because I find that it's more a positive way. And that he does communicate. And the majority of us communicate first with our language, whether it be our eyes or our emotion in how we encounter with other people.

So, that's why I think it's more positive to state it in that aspect. I also, as she stated, I'm an employee of the UM MIND Institute and the resource center. I'm part of several different boards and also created my own foundation. Because I found that it was -- I wanted to be able to give back to community members. Especially community members that have a child that are African-American to help them to somehow bridge the gap of disparity. Whether it be through knowledge of what they need to know to get information or learn in how to advocate for their child.

I will say during this time, one of the things I focused on with my son and I is mental clarity. And mental clarity for me is more so -- it's just checking in with myself. And checking in with my son. Because adapting to everything that has changed, we're all doing something different. One of the things is always to know is we're mentally okay. Meaning

mentally understanding what's going on. And as a single parent, understanding what's going on with him and understanding how distance learning works for him and maintaining working from him.

with that I wake up earlier in the morning. I apologize for the noise you have to hear, that's actually my son. I went earlier in the morning to have the quiet time that's just me and I. Whether it be to get into the word, my Bible, or any praise and worship to start the day off in a positive way. And then I also allow for myself to kind of unwind and do activities of enjoyment. And being a single parent, most of those activities of enjoyment come of having that time to sit and do nothing and not where my mind is constantly moving.

And then we try to do a schedule with all the stuff that has gone on. But I make that schedule pretty basic. Meaning I want to allow for flexibility. But the schedule comes into play, kind of like even has said prior to me. It's just more you do the basic things. You know you're going to have meals. And you know you're going to do some type of activity or cleaning. But I know when I wake up, it's a mental part that I realize if my son wakes up to where he's agitated or frustrated, we're going to do activity more so in the morning. And then that's going to allow them to get some of that frustration out.

And then if it comes that he's less that way, we will do more activities that are more at home. To where we're developing life skill asks stuff at home. So, it works better that way to -- I know that I have a mental schedule that occurs every single day. Depending on how I could work in my schedule into how he wakes up in the morning. Because the big adjustment is for him is because everything has been, you know, moved from him. Whether it's school, being able to go to church. All those different things have been to a struggle for him.

And host of the things, I don't explain in detail to him. I just explain that everybody's being affected by this and we're having to make change. So with that saying we also take care of our body by going out and doing an activity. We do our social distancing. And I will say, what I like about social distancing is being that my son doesn't get the social cues. And he's a very social person. That it helps because

everybody is doing their best to keep their social distancing. So, I drive places to where if you know there's a distance or a secluded area that we could get a good brisk walk in early in the morning or later in the evening. And then still feel connection with others. Whether they're waving, they're pretty plenty. But everybody knows, you're enjoying that encounter and contact. But yet you're still connecting with others.

And I also -- I try to stay present in the moment. By taking each day for what it is. I find that looking forward, look way into the future like, you know, what his school is gonna be like or what work might be like, you find your mind is constantly thinking about and staying sane in the present moment. So, staying in the present moment, you get more things just staying into that day-to-day.

This other one I like is when I speak about the day-to-day. And I chose this picture because the calendar kind of shows it. It's like, you know, we all had calendars and schedules and you're following that, and I figure at this point in time with this virus, it's literally you have to X it out. Because it's going to be whatever you can make it for me. And as I have spoken to other families, of what you can do for that day. So, you're looking to, like support. What kind of supports you have? For me, with as far as I learned I needed to connect more so with families so they could have a better understanding at how to care for my son if something occurred to me.

Which I thought is led me to go into what it takes for something happens if it's just he and I. You know, I did notes where I took telephone numbers of people that are important and wrote them and had them placed somewhere in my house and made those more so of emergency purpose type things that are occurred -- that would occur to something that occurred to me.

So, this virus kind of helped me to think with me being a single parent, it's just me and I here. Things of emergency purposes that I didn't think about, you know? And part of what we did with social distancing and staying connected to people, I got into writing letters to people. It's the old fashioned way of doing things. You know? Writing letters to people. Connecting people, like sending

people through my church. We sent them songs, or we send them messages to kind of keep them encouraged, right?

And then when it came to my son's schooling, which is more of a challenge, I learned to be kind of creative. That creativity came into where I knew what his goals were with his IEP. And he had a lot of goals. So, seeing that we have nothing but time and there's no, you know, constraints on the time, that we would do certain things like, good example, we took the dishwasher out. It would normally take me 2 or 3 minutes and it took him 15, it worked well. You're not pressed to the schedule of time. He's learning to deal with a lot of independence. There's no pressure to think, I got to go here or there. You're at home most of the time.

So, it allows for that to release of those restrictions of time. And to develop those skills in some of our kids. Believe it or not, whether it's allowing more -- I even got him engaged even with my work. If I'm doing a webinar or whatever. So, I'm engaging in lives -- that we would normally do out in the public. I'm doing those at home to help us to make sure that we're continuing to be distant from the community, but yet still a part of the community.

And then with spending the time outdoors, I find that very helpful because like I stated before, the social distancing, we still do. But we do to where there's so many secluded areas that I have found in driving. That driving and being out and still being out to exercise and being a part and still feeling a part of the community has really helped us a lot. An example like today, before I actually got on this call, I needed him to know that he might be a little anxious after sitting for a while. We got up extra early, went for a walk for a mile and a half and then went to the store which you're also exercising social distancing. Got a few things. Exercising and coming home and putting things away and doing those things and washing our hands. So, that way we still have to -- which I also thought of those things prior to knowing that I was going to have to do this.

So, that was that day-to-day schedule. But it helps in a lot of ways. It helps to get us out, get us active and get us in tune with our body and our mind. And this that I did I thought is very useful for me.

Just kind of a basic thing to follow. Find an outlet. My outlet was making sure that in the morning when I do get into my word, reading my Bible and getting into prayer, a praise and worship song, the next one is the music. I get into doing a stretch, which it's good to stretch your body. And we're doing a lot of sitting at home. Stretching our body is very helpful.

So, we found that outlet, that was an outlet for me in the time he was sleeping since it's just he and I. And playing the music today. The majority of the music is Christian music. And I play it throughout the day because it's very uplifting for me. And keeps me, the words minister to my spirit and helps me. And it helps my son because he missed staying at home is going to clutch every Sunday. He put his church clothes out and shoes and shirt on. And I explained to him, we can't go today, and I don't know when we can go. And we sometimes do YouTube. It's another time to spend together where I find a service. Usually he's okay with that. But that's something we kind of do. I kind of have to deal with to keep him encouraged.

And the other one is to read encouraging and uplifting messages. I send those out to other people and single parents and family members. To check in on them, give them a word of encouragement. We all know that we're not alone. But something about someone having a thought and thinking about you and reaching out and saying, hey, how are you? How are you doing? And then sending some type of encouraging words.

And every day I focus on the positive. There's always a positive to look at, to me, throughout our day. I see growth in my son every day. I see growth just in me in adjusting to another aspect of how we're doing, how I'm doing parenting and how I'm going to continue to help him to learn even though he's at a high school age, you know? We're still focusing on that. So, each day I'm grateful for the positive, whatever that brings us.

I go to bed thinking of something positive and I wake up thinking something positive. And that gets us through the day. And with staying informed and being healthy and safe during these times, I find that I stay informed by connecting to the committees and board members that I'm on. Sharing them with the

community that I'm trying to help to keep them informed. And staying healthy by how I eat and how I exercise. We also changed that in the way we eat. We eat a heavier meal early on in the day to allow our bodies to digest and work it off. Not just changes physically, but to nourish us mentally. Because that mental aspect I think is important along with that spiritual aspect.

And last part is just kind of resources. A lot of resources here. Obviously I'm in California. But a lot of resources to where I kind of keep up on things that are going on and I share with family members in regards to wellness and in regards to helping families to assimilate how they could, you know, help their child going forward when they go back to school. And just to share to where they can stay abreast of what things are going on. I'm grateful for this time to spend and share some of the things that have been going on with me and my son and I look forward to any questions that anybody might have. Thank you.

>> Ilka Riddle: Thank you, Benita, that was wonderful. We appreciate your sharing with us. And those in the chat looking for resources, download the slides and we'll have them available for you that way as well.

So, next I would like to turn the virtual stage over to Fran Goldfarb who is joining us from our California LEND at Southern California Children's Hospital Los Angeles to share some thoughts and reflections on today's webinar. So, Fran.

>> Fran Goldfarb: Well, thank you. And it's an absolute pleasure to be here. You know, in preparation for this webinar, or coincidentally, in California, we have been doing a large-scale reaching out to community-based organizations to see what they have been hearing from their communities and also how they're sharing information with their communities. And -- and what are they hearing as far as the needs of families? And it's really pretty interesting how, looking back at some of their responses just absolutely coordinate with some of the things that we have been talking about today. And I think that one of the themes that has come up is this idea of there being too much and not enough.

And I think one of the things that we're hearing is in some ways there's an overabundance of

resources. And -- but those resources -- sometimes it's hard for families to take advantage of them either because they're not working, or they've run out of resources by the time somebody gets to them. Or families may not know how to use that resource. But also, it's just hearing that there is so much information coming at families that it's hard for them to sort through some of this. So, you know, we see too much and not enough that feels really practical and doable.

So, as I was listening to the presentations today, it felt like that was a theme that I was hearing throughout these presentations as well. I also very much appreciated Kara's message about that we can't make assumptions about what families look like and what family needs are and who is going to be the person in the family that is -- that has particular needs and so that we have to have this very open view of who families are and what their needs may be instead of what we think or know what their needs may be. I was also particularly struck with the idea of this looking at policy and the importance of sharing our voice. But again, being able to moderate that with what is actually doable and not spreading ourselves so thin that we're not able to be effective. And, you know, and I think about my inbox in the morning. And there's 80,000 different agencies that are saying, oh, you need to advocate for this. Or you need to be raising your voice about that. And in thinking about where we put our voice with policy, are not only what is needed now, but also some of those adaptations that may threaten or weaken some of the policies that are in place, you know? And we're looking in particular at things like IDEA where we're saying, well, how do we adapt IDEA so that it's doable now? But does it ultimately weaken when our services and supports are?

I was also thinking about Celia's practical tips. And they are so common sense and so, absolutely usable. But I was also thinking of something that I heard years ago as a presentation at AUCD, no plug there, and I'm paraphrasing it because I don't remember the exact words. But again, there were so many solutions and so many supports out there. But to the truly tired person, those resources and supports feel like one more thing to do instead of help. And

how do we support families in being able to come up with resources that feel supportive as opposed to feel like one more thing to do?

So, you know, just being able to do some reframing focusing on strengths I think is incredibly important. In kind of reflecting on Carol's presentation, I was struck by the fact that Puerto Rico is dealing with a disaster on the tails of the disaster. And how do some of the lessons learned from Maria kind of translate to the current situation. But also, how are we testing the resiliency of people and making sure that the supports are not only for what is going on right now, but also take into consideration where families have been coming from.

I also think about the importance of translation and what we're hearing from so many families is that things may be available in more than one language. But sometimes those translations do not make the materials particularly useful. And so, this attention to translation being correct and also being in plain language so that it's -- it's usable.

And lastly, just coming to Benita and, again, some of her very wonderful tips about how do we sort of maintain normally in a time that's completely abnormal? And how do we make things feel consistent and safe for our family members when we may not be feeling like things are particularly safe and consistent? And so, some of those strategies for just being able to continue on are so very, very important. I'm gonna stop now because I know that we do have some questions. But I hope that this is useful as well. Thank you all and take care.

>> Ilka Riddle: Well, thank you so much, Fran. That was wonderful. I'm going to pass it off to David Deere who will be fielding our questions. He's our official Q and A marshal. He will be leading that. So, we have a few moments for that. I'll pass the first rule -- the stage over to you, David.

>> David Deere: Thank you. Wow. What a -- what an event. This was just packed with great information. And among other things that we heard, it's great to be reminded about the importance of self-care. Especially at this time. Our ability to help our families is directly related to our personal well-being. And we have to first take care of the caregiver. Then we're able to care for others.

And we appreciate the speakers who have reminded us of that important point. And I would just say, Miss Shaw, we had a ton of positive responses to your presentation and your positive and upbeat approach to everything. We do have a number of good questions that we'll get to as many as we can. We do apologize for losing the chat box and the history there. But I want to start by addressing the -- probably the most of the entries in the chatbox were about certificates. And I know that Adrienne addressed that several times. But it might be helpful to do that one more time just vocally for everyone.

And particularly for the people that typed in that they wanted a certificate. Do you need for them to send an email? And then if you could also maybe highlight the collection of stories on COVID that you're doing at AUCD. And also, we had several questions about where do people get recordings of last week? If I could just toss that to you, Adrienne or others at AUCD.

>> Yeah, this is Adrienne. I just popped up in the chatbox. We do need you to submit your official request for attendance certificates to NationalCenterph@aucd.org. That was one item. The other item was looking for the link to the webinar series. That is a longer link. It's available on the AUCD webinar library. I can also share that link in the chatbox as well. And then you asked me something else, David, what was the other point?

>> David Deere: The other was about the collection of stories. The experience with COVID.

>> Adriane Griffen: Yes. We are doing that online as well. Your stories are important from a policy perspective as well as a programmatic perspective. We have an online form for that as well. And I'll put the link for that in the chatbox as well.

>> David Deere: Okay. And we have a question -- do you have any culturally-specific terms on coping, stress reduction or trauma responses in relation to caregiving and multiple trauma fronts in the case of COVID? That could be addressed by any of the speakers. A couple of them mentioned either cultural or linguistic approaches that they're using. Carol, I know you mentioned something about translating materials and?

>> Carol Salas Pagan: Yes, one of the things

we're trying to stay on top of is looking at materials that not only AU CD, but other I/DD organizations are shared in English. By ACL or other agencies and we are trying as we can to translate them into Spanish. But you could -- I could give the persons my email and you could ask me for more detailed material and I will surely share with Adrienne or any to the persons that write to my email about Spanish information about resiliency and stress and recommendations for COVID and for other information that you need. We will be very happy to share those in Spanish.

>> Benita Shaw: Hi, David. How are you?

>> David Deere: Doing well, Joni, good to hear from you.

>> Benita Shaw: At the center for START Services, we have several teams in California that have very diverse teams providing therapeutic support and outreach to families in California. And what I can do is send a connection to the director of that program because I think they are doing a lot of work in with regard to cultural competency. And we have a team in Texas with those supports that are Mexican Americans. And there's outreach around anxiety and depression and social isolation. I can give you my email address and then you can reach out to me and I will forward -- I will forward you to the right people.

>> David Deere: We are also getting postings, looking at the chatbox, there are other resources. One thing I would just add for the folks that are involved in the programmatic or advocacy side, just to be mindful of the adverse impact that COVID is having on groups of color as well as people with disability. People who are living in poverty, homeless. Those special populations that are really being adversely affected.

And Carol one other thing that I think a lot of the UCEDDs would be interested in seeing would be the protocol for COVID testing for people with disabilities. That might be a good thing to share with the network.

>> Carol Salas Pagan: Yes, actually what it is is we developed it in plain language and the goal of the protocol is that if a person with a disability needs to be tested that they don't to go through the all the bureaucracy. That they could just call and give either

an appointment or that they could get an appointment for some lab to come to the home and do the testing. That was the first part of it. But the second part we included and are advocating for is that, if you test me, and you should also test my family members. Because probably my caregiver or the person who is living with me or taking care of giving me my support person would be the person who is probably infected with the virus. So, it makes sense that if we are living in the same home and we are coming here to do the testing, why not test all of us to prevent the continued spread of this virus? So that if the other part that we are advocating for in that protocol. And so, yes, as I said in the presentation, the part that we are waiting for is the final approval of the Department of Health. Especially we're trying to wave that the person with the disability or the director support person doesn't have to get an approval of the primary health care person. That they could just call the lab and get the testing. So, that is taken into consideration right now. So, as soon as I had the cue, I will share it.

And it's in Spanish. I will make sure I translate it into English. And I will share it with Adrienne and all the network. I will. Thank you.

>> David Deere: Okay. We have another question. A big worry is providers of services will begin to say you did fine without that nursing hour or that therapy reduction. So, we'll be cutting your future hours. What would be your advice about that, please? That's not directed to any specific person. Any of you that have thoughts about how to address that? We did have one response in the -- in the chatbox after that question was asked. And ha said to try documenting regression and putting it in writing to the insurance provider. Get a doctor's note or a supplemental document that demonstrates regression and the need for the service to be resumed as it was. That was one comment. Are there other thoughts or ideas? Make just not on an individual basis, but group advocacy to do to address those sorts of potential cuts

>> Fran Goldfarb: This is Fran. That's one of the items we are worry about that corners are being cut by necessity. But we don't want to make sure that we're turning squares into circles forever. And

so, you know, as we look at both individual services and policies, it's important for there to be advocacy around the notion that these are temporary and made necessary by very unusual circumstances. But that this is not what we're looking at as far as being optimal or even adequate on a long-term basis.

>> David Deere: Thank you. Let me ask Adrienne, do we have time for another question? Or are we at the end of our hour here?

>> Adriane Griffen: Well, thank you, David. We are wrapping up. I'm going to turn the virtual assistant back to Ilka to wrap us. Thank you, David.

>> David Deere: You're welcome.

>> Adriane Griffen: Ilka, this is Adrienne, if you are speaking, we cannot hear you. Give you one more second.

>> Ilka Riddle: Can you hear me now?

>> Adriane Griffen: Now we can.

>> Ilka Riddle: Fantastic. So, sorry, yes. We are unfortunately out of time for today's webinar. Thank you all so much for attending. As you know, the webinar has been recorded. And the webinar will be available and archive the in the webinar library at AUCD.org. After this webinar there is a short survey, we would love you to fill out to give us some feedback. And then, of course, we would love to see you next week for our third of our four-part webinar Wednesday April 29th at 4 p.m. eastern. And we will concentrate then on advice from self-advocates for other self-advocates. And wrap it up with you getting your questions answered from our experts. So, thank you all, everyone, for attending. Have a great morning, afternoon or evening, depending on in which time zone you are and from which time zone you called in. And thanks for the rich discussion in the chatbox and for always sharing lots of resources and links. Thank you all very much. Have a wonderful rest of your day or evening.