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**AUCD-COVID-19 and the UCEDD Responses Across the Network-(Adobe)**  
**Association of University Centers on Disabilities (AUCD)**

[STAND BY FOR LIVE CAPTIONS]

>> Anna Costalas: Hello! And welcome to COVID-19 and the UCEDD Responses Across the Network, my name is Anna Costalas I am the resource manager here at AUCD I would like to thank you, all, for joining us today, before we begin I would like to address a logistical details because of the number of participants your audio lines will be muted throughout the presentation, however, we will unmute your lines at the end before the Q&A, you can also submit questions at any point during the presentation via the chat box on your webinar console you may send the question to the audience or the presenters only, we will compile your questions and address at the end. Please note we may not be able to address every question and may combine questions, this entire webinar is being recorded and will be available at AUCD's webinar library. There will also be an evaluation at the close webinar. We invite you to provide feedback interest the webinar and suggestions for future topics, I will now pass the microphone over to Meagan Orsag, chair of AUCD's community education dissemination council. Meagan?

**CART FILE**

>> Meagan Orsag: Howdy everybody! Thank you, guys so much for joining us today.

My name is Meagan Orsag. I am associate director at the center on disability and development at Texas A&M and also the chair for the community education dissemination council and we serve as a focus for the identification, and discussion of issues, regarding community education, and information dissemination, we also serve as representative voice of the community education interests, and concerns within the network. And we influence development and implementation of national communication, community education, and information dissemination policies and initiatives.

It's been a joy to be part of this council. I am so proud of the work that all of the members have done, the past three years.

We have a link here on the slide. If you have an interest in joining us in our LISTSERV, but we're excited to host this -- cohost this webinar, with the emergency preparedness SIG. Especially in light of COVID, and the response that we've seen throughout our network.

I'm going to go ahead, and pass the baton over to Amy Sharp and Laura Stough, who will be our webinar facilitators, and they will introduce themselves, and give a little bit more explanation of the webinar, thank you so much!

[An electronic tone],

Hello everyone, this is Laura Stough.

I project research and -- assistant director at the center on disability and development here at Texas A&M university. I also chair the emergency preparedness SIG for

AUCD. I want to thank the community, education and dissemination Council, for inviting the emergency preparedness SIG to collaborate on this webinar.

The emergency preparedness SIG, meets regularly, at the annual AUCD meeting; hosts webinars, disseminates materials and information, and it has over 150 participants throughout our Network.

Dr. Stough: In most states right now, emergency management is working hand in hand with the partners in state health, in response to COVID-19.

And in some states, including my own, the Division of Emergency Management, is in fact, the lead agency, for response to the pandemic.

So our emergency preparedness SIG is more important than ever, and we would love for you to join us. Please look on the AUCD Web site, under the issues tab to join our LISTSERV and note that there is a couple of steps that you'll have to take in order to do so.

Dr. Stough: I want to thank you, all, again, for attending this webinar today.

And many of you, it seems like, spending quite a bit of time, on these webinars. And on Zoom.

But in planning this webinar with Meagan Orsag and Amy Sharp, we wanted to make it less of a talking-heads presentation and provide a fast-paced, resource-rich, sharing across our network.

What is different about this current emergency, is that all of the U.S. is experiencing this pandemic. Not just, you know, tornado-prone or hurricane-prone, or flood-prone areas.

So all of our Centers are being affected

And we realize that we're producing, creative, just-in-time products and projects to address, the needs of people with disabilities during this crisis.

And those products and projects will be what we will focus on today.

So I'm looking forward to hearing from my colleagues, over the next 36 minutes. We have 12 Centers represented here today; and each are asked to strictly limit their presentations to three slides, three minutes, and one product or project. So this webinar will go fast! I'm going to pass the mic, and we will continue on.

(A pause)

>> Howdy, this is Meagan Orsag, again!

We will be -- these are the 12 presenters. We are so excited for them to share their expertise with all of us! And, again, like, Laura mentioned there were three slides for three minutes on one topic area!

So, buckle up! Thank you, guys for being here, and Beth, you are first! Thank you so much.

Beth Potter: I'm the director of information services at the university of Kentucky human development institute.

And we believe that the UCEDDs and HDI were built for times like these. Our mission to promote the inclusion, and independence and contributions of people with disabilities, and their families, throughout the life span guides our work, and in the best of time, that are challenges, opportunities, for growth; and much work to be done. But during the worldwide pandemic, the significance of this work is heightened and it has taken on even greater meaning.

Beth Potter: We are charged with continuing to educate and share information, that can increase the capacity of our partners, while helping those that we serve. During this difficult time, one of the many areas where we were well-positioned to remain flexible and be responsive is event planning and presentations. HDI hosts many events that are typically offered face-to-face. And while some scheduled events had to be cancelled, we were able to continue

most of them without interruption.

Beth Potter: For HDI, this provided a unique opportunity, to demonstrate our ongoing commitment to utilizing the principles of universal design to host events virtually using available tools and technologies.

For example: HDI had planned a wellness event to increase, people with paralysis, shifted our plans and hosted a 1.5 hour live event via Zoom and YouTube streaming. Approximately 300 and 50 participants interacted with presenters and each other to do zumba yoga and learn about the arts and nutrition.

We found, through evaluation of a two-hour panel discussion, about supporting students with significant disabilities in and their contributions to the workforce, that an exclusively virtual moderated event with live captions can be well-attended, engaging, and perceived to be of high quality.

We have recently mobilized tech support, offer technical assistance, to presenters, and survey participants about virtual platform preferences, to inform the reconfiguration of an overnight summer leadership experience for high school students.

This event that is usually held on UK's campus includes topics such as financial aid, independent living, accommodations and more, will be delivered virtually this year.

And although we have always evaluated, HDI presentations, these results are especially helpful to us now. We reviewed the feedback immediately to identify ways that we can increase our capacity, to deliver high-quality events.

Making changes in event planning and presentation is only one example of how we have shifted operations to meet the needs of Kentuckians and our

staff during this challenging time.

On behalf of Dr. Cathy shepherd Jones and the human development institute, we encourage you to visit our Web site at HDI.UKY.edu, and review the extensive COVID-19 resource page that we have created. Thank you for this opportunity!

>> Mr. Bill Gaventa:

Good morning, everybody. I'm Bill Gaventa. I am part of the national collaborative on faith and disability, which connects a number of the UCEDDs around the country who are interested in spiritual supports and inclusive spear supports. We've done a webinar about COVID, also been doing -- helping do some other things related to the kind of dealing with the fear and loss and grief, that's going on, with all of this.

The -- there was an editorial in the Waco paper -- I forget -- by somebody's name, talking about the loss and grief, and said it needs a soft place to land. Which really struck me, because, a lot of people with intellectual and developmental disabilities and others, grief has not often been welcomed or had a soft place to land. It's sometimes been acted out, disenfranchised, or other ways of people not recognizing it. So it's clear, I think, for everybody right now, how do we help find ways to recognize and welcome grief? To create a safe place, for it; that usually is going to be with relationships that people -- for somebody who knows somebody well. For all of us to be -- for people to be very alert to behavioral expressions.

And to help people who are wanting to support and comfort, others. To do all the typical, normal ways of acting out, like, talking about feelings and memories, cards, photos, letters, calls -- whatever,

To help support people, who may be, have lost somebody, or worried about that. Or someone in the hospital.

Bill Gaventa: There's some great loss and grief resources right now related to COVID-19 on the hospice Foundation, at the Hospice Foundation, I've got a fairly long listing of resources on grief and loss, not necessarily related to COVID-19, and then there is some wonderful picture -- adult picture books from Books Beyond words in the U.K., which if you've never seen it, take a look at them. And some of them are specifically for COVID-19, some of the feelings down there, they're downloadable and useful. And key strategies around grieving. Accurate and honest information,

About it enveloping -- enabling maximum involvement, and keeping connected, supportive relationships, and just maximizing opportunities.

I've got some webinar links there to some -- ones that we -- we have done, or people have been connected to that recently.

And finally, one of the ones we did, that -- this slide is from Christian horizons, a provider organization in Canada, that's done a really nicely-curated Web site, around resources, related to COVID-19.

And they've collected a whole bunch of them in plain language; and I've sent our slides on today to them, so they can add some of the ones that you-all have done. Thanks. But help people pay attention to the fears of loss, and grief. Have a good day

>> Elizabeth Turner: (Taking the podium) hello, everybody!

My name is Elizabeth Turner. And I'm the associate director of communications for Vanderbilt Kennedy Center in Nashville, this is my first AUCD webinar I've participated in so I'm in illustrious company. I'm excited to tell you a

little bit about some of the material that my team and I have put together to help inform and alleviate stress, in our families, and individuals with disabilities.

The first one that we did, our efforts began in in mid-March, when schools in Tennessee started closing temporarily or at least we thought they were going to be temporary. And the concept of social distancing, was starting to grow.

And pervade our news cycle. Our communications staff worked alongside our coworkers, to create new materials that would be easy-to-put-together and to share quickly through our social media platforms. Two of which, we created, are seen here, which are visual supports on proper hand-washing and explanations, why community engagement is being limited.

All of our materials, which have been created in-house, have been tagged and have been made accessible for screen readers.

From there, we started adding these and other external tools that we've been finding to several dedicated COVID-19 resource Web sites. Including the two you see below. In this graphic.

Which is our Tennessee disability pathfinder, UCEDD information and referral service, as well as a separate page on our I/DD healthcare toolkit, which is a resource for self-advocates, family members, and healthcare providers.

Elizabeth Turner: Shortly after that, we received a request in our VKC general inbox from Ohio, asking if we had known of any social stories out there, about ventilator use.

Our treatment and research institute for autism spectrum disorders also known as TRIAD, that team got to work right away, collaborating with pediatricians within the Monroe Carol children's hospital at Vanderbilt to create both on intubation and extubation social story, which you see here.



Both of these are on those two Web sites that I had mentioned previously, as well as TRIAD's own COVID-19 page, which is chock a block full of tip sheets and archived webinars based on telehealth assessment. Distance learning and so much more.

There is a lot to discuss about TRIAD's individual efforts during this pandemic that wouldn't fit into these three minutes. If you're interested in learning about the resources we've created please feel free to reach out to me Elizabeth.Turner@VUMC.org, for more information, so thanks for having me, and thank you for your time.

Larissa Yoshino: Hi, my name is Larissa Yoshino, and I am the data and dissemination coordinator, at Oregon Health, and Science university institute on development and disability. UCEDD LEND, this resource demonstrates our responsiveness to community need with a focus on health and quality of life. How to be social while physically-distancing is a ten-minute voiceover video presentation, that was created, to address social isolation, which is, of course, a common challenge that has only been intensified during this particular time.

Of stay-at-home-orders, near the beginning of Oregon's stay at home order, one of our staff actually had self-advocates calling her; and asking about what they should do.

And this led to compiling a list of all the possible ways to combat loneliness, disconnection, and boredom.

The resulting product was a collaboration with the Oregon Office on Disability and Health, who are frequent partners on our health promotion efforts; and community self-advocates.

This presentation starts with briefly, explaining what COVID-19 is, and

what social distancing means. And why it is important.

And then most of the slides, are suggestions of ways to stay busy; connect with others; and take care of yourself.

Some slides not pictured, include.

Walking outside, and waving Hi, to people from a safe distance.

Having online movie or game nights.

And trying new social connection apps.

We attempted to make this information as accessible as possible, with lots of visuals, plain-language, image descriptions and captioning, for the video voiceover.

And a downloadable PDF version is also available online, with active hyperlinks on the slides.

Larissa Yoshino: (Continuing) the voiceover for this slide says, "Remember, that being physically-distant is hard. Especially for long periods of time."

Don't be afraid to reach out to your friends and family, to ask for help or extra support, if you are lonely and sad.

Larissa Yoshino: We especially wanted to acknowledge that people might be having a hard time, and make sure that they had ideas, and resources, they could act on right away.

This practical approach with concrete information that can help people feel less alone, and -- has been well-received by our Community so far. And you can find this and more on our Web site, which is [OHSU.edu/UCEDD](http://OHSU.edu/UCEDD).

Thank you! Scott N. Mullins: (Taking the podium) hello everyone, I'm a licensed master social worker and I'm the transition specialist at the institute for

disability studies, that's located in Hattiesburg Mississippi on the campus of university of southern Mississippi, so during this time, with COVID-19, it's been difficult for our members.

They like to do a lot of social engagement, interaction, which we had basically every day and then it went to every one has to stay at home. Everybody was disconnecting. So me and my team got together and we decided to use this particular app that I'll be discussing DISCORD to try to engage our individuals, so -- DISCORD is basically a digital platform, social media, it was created in 2015, originally created for the gaming community. However, we've used it to utilize with our members, some of the best thing about it is that it's free, so you don't have to pay anything, you can get it as an app or use the Web browser, it works across multiple devices that support windows Mac OS, Lennox and one of the things is uses different channels in the main group, you can list channels where you can list chat channels and text channels, this is how we were engaging our programs, such as step-up to leadership council. Which is our student inclusive organization.

And then our TRIAD AmeriCorps, our service organization, if you have time, the link down here takes you to our self-advocacy coordinator, he made a video that, welcomed in the visuals to come in and create their own DISCORD. We've used in particular ways.

So engagement, we're utilizing the different benefits and connection media that DISCORD offers so like I said -- you can do text, audio chats, gifss, photos, and video messaging, whether you're finding a video online hosting it or you're creating your own video. We're using it for different socializations so we break those down into different groups, if you look at the bottom picture you can see

stuff lined up on the left side going down, so our socialization, we have these different interest groups, movies, the Internet, video games, fashion, community involvement, sports, anime, and just we've listed a lot of different opportunities for our members to really engage in those particular topics that are of interest to them. We also are hosting different recreational events.

So this, to include our individuals, so we're doing "Dungeons & Dragons", our role playing game, and table top, which is done through a tactile simulator. Hosting trivia, two nights a week, "Dungeons & Dragons" is two nights a month and this month we're hosting scavenger hunts virtually. So thank you, again, for having me here today, and if you have questions contacts me at Scott.Mullins@USM.edu.

>> Hello everyone my name is Tara Lutz from the university of Connecticut UCEDD, I am partnering with our developmental disabilities network coordinator Linda Rammler on this, I serve as the training director. What I wanted to share with you-all, is our main Web site, that was created in order to house all of the information that's coming out, related to COVID-19, we -- very early on, recognized that as a UCEDD, we serve as a knowledge broker for the state of Connecticut.

And in doing such, also, recognize that there is information overload out there.

Tara Lutz: So the link you see on this page, was created by our -- underneath our center leadership, with all of our UCEDD staff.

To serve as an information Hub of resources, for individuals in the state.

Another thing that we've done, related to COVID, is we partnered with our cross-disability life span alliance group to ask people -- these people include

parents, family members, advocates, and providers, how they're staying connected during this time.

And how we can be helpful in facilitating virtual or distance-related gatherings.

And this has resulted in a calendar that's available on this Web site. Hosting a number of different events, not limited to morning meditation. Coffee conversation, sign language classes, cooking classes and even discussions on the Netflix documentary, "Crip Camp", this page demonstrates how we've broken down our resources based on category, or who is accessing said resources.

And this is Linda Rammler: I am the developmental disabilities network coordinator for the U con UCEDD and Tara is my colleague. There are two things that are on our Web site, that have gotten particular attention with respect to emergency preparation.

And assisting people with disabilities during this pandemic.

They're both flipbooks that we made specifically for first-responders. The first one was made several years ago. It's the one on the left of your screen, prep is personal, find the fridge, and it is broken down by disability category or responsibilities, and it contains specific Access, and functional needs, as well as unique ways of interacting, take with, in case the individual needs to evacuate. And also cross-referencing with other disabilities for people who may have multiple challenges.

The flip-book on it right. Communication aid for emergency personal was developed by actually -- came with an idea that came out of our LEND cohort from 2018 to 2019, who suggested that first responders, also needed a way to communicate. So this flip book has different types of communication, options

available. Ranging from I think that's a cue for me to be quiet. And they've both been very popular. They're available on our Web site, thank you. Catherine Ipsen: Good morning! (Taking the podium), I am Catherine Ipsen. I am the associate director of the University of Montana rural institute for inclusive communities, and the PI on the research and trainings on disability in rural communities, and I am here -- wearing the latter hat, to describe research that we've done, looking at rural implications from COVID-19.

So we utilize, in some of our work, secondary data sources, and, we use those sources, to be able to tell a compelling story, and so the map, that I'm showing here, is looking at counties across the United States, that do not have ICU beds in them.

And, so we start with a story that we want to tell, such as people with disabilities, have a narrower margin of health, greater risk of chronic health conditions; and may need to seek, medical care, and in particular, intensive care services, at higher rates.

As you see, in this map, there are huge, vast swaths, particularly in the middle of the U.S., that are a long distance from ICU beds.

And that has implications. Barriers, such as transportation, travel time, financial burdens, that place this group of individuals, at particular risk.

And so it's an opportunity to really showcase this, and get information in the hands of emergency preparedness folks to really look and think about this, as they're looking at a COVID, uh... kind of bloom in their areas. (Table: "Counties without ICU benefits).

Next, we also have used data from the (slide: Economic hardship) survey of household economics and the American time-use survey.

To explore how rural people with disabilities, might respond to some of the economic hardship coming down the -- down the pike. We know that rural people have not recovered, from pre2008 Great Recession employment rates, so they are still, kind of not back to where they were, and it left many of them vulnerable to economic hardship.

With the data from the survey of household economics we found that 66% of rural people with disabilities have no emergency fund. And 30% could not cover an unexpected \$400 expense, so looking at some of those implications, in combination with a -- another Recession coming down the pike, is important. And then the other thing that we looked at, was for those who are working rural people have less opportunity to transition to telework. And/or have paid time off to address illness.

So, in particular, rural people overall, have less paid leave, and less opportunities to work from home.

But in addition to that, people with disabilities, have lower rates of that in their employment.

So, they're at particular risk for having adverse economic impacts, even for those who work.

And we tried to use this data to really tell a story, that people can use to advocate.

Thanks (Catherine Ipsen).

>>

Dr. Salas-Pagan: Good morning, everybody, I am Dr. Salas-Pagan. I am the Puerto Rico UCEDD director.

And I'm very glad to be here with all of you this morning.

So, between earthquakes, and COVID-19 -- the last earthquake happened just this week here in Puerto Rico.

I don't know if you heard, but between COVID-19, and earthquakes, our UCEDD has been given continuing -- giving services especially to our family-to-family center, our two child development centers, are also working remotely, and giving phone, and online services to our families.

Dr. Salas-Pagan: As many of you are doing, we are giving webinars on different topics, trying to keep people connected.

We are participating twice a week, on the core advisory group calls to keep track of the handling of the needs of people with disabilities. Between earthquakes and COVID-19.

So we keep on working with translating material; making the Puerto Rico medical task force information accessible; and in plain language, as many of you are doing. But being part of the medical campus of the university of Puerto Rico, which is in charge of the medical task force, for the Government, we were very worried, and being aware of the challenges that people with disabilities, have to access healthcare, we were very, very concerned about the accessibility to getting tested for people with disabilities.

So -- what we did we developed and submitted articles, with recommendations trying to advocate on behalf, and trying to guarantee accessibility to COVID testing, not only for people with disabilities, but also for their family or household members. So we developed it, and we got the feedback for all people with disabilities, and of families of people with disabilities, from a consumer advisory groups, and other stakeholders.

So what we did. Is that we started requesting that COVID-19 testing be



done at home. We know people with disabilities are at increased risk for COVID-19, and as we are aware, people with disabilities and their families may face a lot of challenges, having access to healthcare in general, but having -- we were aware that they might end up having accessibility issues, to get tested for COVID-19.

So we recommended that, testing be made at home, not only because of accessibility, but also, to protect them, because of other concomitant conditions that they may have, that may be at greater risk of -- having health complications, so the current situation in Puerto Rico is that the doctor is the one who orders -- you do need a doctor's order to get tested for COVID-19.

Because of the relationship between the family members, and the person with disabilities, care-takers, physical distancing we know it might be difficult. So we recommended, also, that doctors issue a medical order for the COVID-19 tests for all the household members, so those were our two challenges, that we made sure we wanted to make sure -- [sic] that they tackle.

So that is my -- on the last slide, there is a -- the last three -- sorry.

So you have there, the what we developed is now in the hands of the health department Secretary, to sign and make the executive order [sound of children in the background], so -- questions?

>> Okay, because (].

>> I'm Andrea Caoili, a licensed clinical social worker and the director of research and quality assurance for the center for Start services at the institute on disability at the University of New Hampshire.

START is a crisis service model of support for people with I/DD and cooccurring mental health issues across a lifespan; and there are 25 regional

programs across 13 states we work with. The start model is based on positive psychology principles. So maintaining connection and promoting hope across our network, emerged as a clear charge for the CSS leadership team, really early on, in this pandemic.

We launched a COVID-19 resources Web page, available on our Web site, and offered a series of free training focused on hope resiliency, and self-care.

We just concluded our START national training institute which was held virtually. We had over 500 participants each day on either Zoom or Facebook Live. And we even held a virtual poster session, which surprisingly, went really well.

And everything continues to be available free of charge on our Web site, or Facebook page.

START teams also collect data for -- around service delivery for people that they support and enter into the START information reporting system, which is a web-based data entry platform that's used nationally by all START teams, we modified our practices to promote virtual interaction, and engagement, and therefore, had to modify our database to track the supports offered and measure effectiveness over time.

We've just started to begin to evaluate this. And we're beginning to really learn a lot about preferences with regard to virtual supports. Among other things.

The other thing that we've done, is we've launched a COVID-19 family interview tool, which was developed by Dr. Beasley, the director of the center for START services, and myself, to really elicit, some input from family members of those supported in START. We were people with I/DD, and mental health issues

are often excluded from typical research activities and we really felt it was important to make sure, that everybody had a voice, because this pandemic is -- is really impacting everybody. In many different ways.

There were two responses that stood out to me, preliminarily, as I looked at the data. We will have a total of 1600 family interviews, available for analysis within the next two weeks.

But these two responses stood out to me. COVID-19 is not the only crisis that is occurring.

Sometimes I think it's crazy that I have three children, with autism, all stuck at home.

This family has actually lost three extended family members, to COVID-19.

And the other family really highlighted, the impact on -- on general emotional wellness, financial insecurities, employment loss, among other things, that are really impacting the stability of this family.

So in summary, you know, CSS is working really hard to build community capacity and resiliency, because that's our mission, we're offering forums to exchange ideas and brainstorm, and also working to understand the impact of COVID-19 on our service users. Which will ultimately, impact all of our practices across our mental health community moving forward.

Thank you. Erica Coleman: Good afternoon, everyone. My name is Erica Coleman. And I work with the university of Cincinnati, center for developmental disabilities.

On projects related to health, wellness, and safety.

Erica Coleman:

Our UCEDD is the lead for the center for dignity in healthcare for people with disabilities.

And the goal of the center is to identify, and reduce life-limiting healthcare inequities for people with intellectual and developmental disabilities, by improving access to antidiscrimination medical protocols.

The center's objectives are it to increase understanding of gaps in existing curricula, policies and guidelines around medical discrimination.

Increase access to antidiscrimination protocols, codeveloped by self-advocates, and family members.

Increase informational access on barriers to healthcare; and the value of improved life outcomes for people with I/DD, and to increase support for families and individuals with I/DD to defend against health and healthcare discrimination.

After COVID-19, ACL, administration for community living, requested the focus change to address issues more specifically related to COVID-19.

There were two factsheets developed that addressed the rights of people with disabilities in healthcare settings.

(Next slide) and the first one, is a factsheet created for people with disabilities, and their family members to ensure that they understand their rights, and what they need to do, in different situations, and if they need accommodations.

You'll see on the left side, there is a list of know your rights, and this provides an explanation of certain rights that individuals have, and on the right-hand side, the title of "act with care" details how a person can adjust or improve their own actions to stay safe. This includes hand-washing.

Doing things to decrease one's exposure to germs, as far as touching

surfaces, and then just avoiding others that, you know -- we know that is not always possible, but in situations where you can't -- safeguards that you can put in place to make sure that you're safe and decreasing your exposure.

The next factsheet is titled "safeguard against disability discrimination during COVID-19."

And this was created to inform healthcare professionals and personnel about the rights of people with disabilities in healthcare settings; and that they cannot discriminate based on health status.

So the first section, of -- think equitable, this is to ensure people with disabilities, are in fact, treated equally. And then it moves on to discuss, knowing the best practices.

So a list of tips, if you will for healthcare providers, red to areas, like, communication, and providing accommodations.

And so that is clear to them.

The factsheets were disseminated nationally with the hope that people with disabilities would use them, and also take them along, when they have doctors' moments. Thank you. ( Erica Coleman).

>> Hi, everyone, my name is Colleen McLaughlin, and I'm the associate director at the Boggs center on developmental disabilities at Rutgers University Robert woods Johnson medical school. Before I get started -- because I'm going to be talking about training we do for the direct-support workforce, I really just wanted to give recognition out to all those direct-support professionals that are providing critical supports to people with disabilities, and their families.

And convey how important it is that we work hard that the recognition that they're receiving now and any potential increase in compensation they're

receiving doesn't end with the pandemic. It's such an important role now, and always.

And thanks to everybody, across the AUCD network, for really working at light speed to make sure that disability and healthcare communities, have the resources, and training that they need to provide ethical and quality support that continues to meet the needs of people with disabilities and their families. So thanks to everybody!

That's doing all this hard work.

I'm going to speak a little bit about some of the trainings that we've been providing over, actually -- a number of years at this point in time.

So we at the BOGGs, center conduct a number of trainings through New Jersey home- and community-based waiver services programs. And at this point in time, some leeway was granted with regard to completion time frames.

But these trainings are still critical, and require concurrence to ensure disability have the skills and confidences they need to perform their roles as essential front-line workers.

And this is especially critical as we've seen an influx of new staff that are continuing to be hired in an effort to fill some of these positions, vacant due to illness, given we're in New Jersey, and there is a wide number of people diagnosed with COVID-19.

As well as a number of people that have needed to leave their jobs, due to childcare responsibilities with school closures.

So this training couldn't stop. We had to keep moving forward, with the classroom training that's required under the waiver.

And as social distancing was moved into place, we had to really move at a

rapid pace, to make sure that these trainings that were traditionally done in the classroom, were able to move to an online format, without losing any of the content that's really necessary, to address competencies.

We also wanted to make sure that we were able to maintain similar CEUs so the people who had taken these trainings in the past received an equitable amount of credit.

Colleen McLaughlin: So we needed to make sure we were maintaining some of the links, ensuring all the content was addressed and making sure we're engaging learners in multiple ways. So we had to really quickly move to adapt these trainings, including revising instructor's notes; adding a number of desktop activities; we developed polls that required that each partner, was engaged, through various increments of the training; and then, making sure that we had cotrainers that were prepared for doing that.

And then just in addition to that: As we were revamping all of these trainings, we wanted to develop a series of trainings that were done, really, in response to the COVID-19 pandemic. So our trainers are working hard to make sure that happened.

Thank you (Colleen McLaughlin).

>> Dr. Laura Stough: (Taking the stage).

... (continuing) on emergency management. Our task force serves in an advisory capacity to the division of emergency management.

And that group today consists of about 80 different stakeholders, roughly half are from emergency management and half are disability organizations, or self-advocates while the remainder are local or state agencies like our state health and human services, which is a particularly key player, in response to

COVID-19.

Doctor Laura Stough: I share the disability task force, Amy Sharp, as director of our sister center at the university of Texas, also serves on the task force. As does the Director of our developmental disabilities council, our P&A, the director of our state independent living center, and our governor's office, on persons with disabilities.

Our FEMA regional disability integration specialist is a member, as are several members of voluntary organizations, active in disaster, and faculty at other universities.

We have a liaison, to the division on emergency management, and we meet quarterly, along with other advisory groups that report directly to the state chief of emergency management.

Dr. Laura Stough: We have 5 goals which you can see here, including.

Providing strategic representations.

Supporting emergency management plans.

Creating tools related to planning.

Enlisting the disability community in emergency planning and response.

And developing training products.

Dr. Laura Stough: In the current COVID-19 situation, goal No. 1, providing input and strategic recommendations, has been our primary focus.

So as the disability task force was already in place, before COVID-19, we were in prime position towards the Texas division of emergency management to call upon us as the pandemic began to unfold.

In late March we were asked to provide a list of resources, pertinent to disabilities, and COVID-19 to the State Operations Center. Together our group



of disability stakeholders, was uniquely-suited vet curate and come up with this list, to forward to the state operations center.

Second: The division of emergency management asked us to provide recommendations directly to them on Disability-related issues, on an ongoing basis.

And this was unprecedented for the disability community here in the State of Texas, to be invited to provide input, in the response phase, and over 41 stakeholders from the emergency management community, and the disability community, have participated on our calls. We've been meeting twice a week.

Discussing, formulating recommendations and then we send those recommendations, immediately out to the state operations center to the Division of Emergency Management. And then finally our stakeholders have developed tools and supports. Some we locate through our networks and we exchange them. Increasing the capacity of our state to serve the Disability Community. If you would like to know more about working with your own division of emergency management, please do contact me!

I'm now going to pass the virtual mic, to Dr. Amy Sharp. Who will provide a summary as well as pull together the presentations that you've heard today.

Amy?

[APPLAUSE]

>> Dr. Amy Sharp: Hi, everybody, so I'm your third cohost, Amy Sharp, I'm with the Texas center disability studies at the university of Texas at Austin, and I have been asked to wrap this up. So thank you, everyone for the fantastic and well--organized presentations!

I know that Meagan will be facilitating the Q&A next, but I just want to provide a brief summary of what we know, and recap what we've learned today.

Just so everybody's aware, the slides are available on your Adobe connect dashboard in the middle at the bottom. You can download the presentation, if needed.

So according to the centers for disability -- centers for disease control and prevention, we know that some populations are at higher risk to get COVID-19.

People who are 65 and older, people who live in congregate care facilities such as nursing homes, jails or long-term care facilities; people who live with high-risk conditions, including heart conditions, diabetes, lung diseases -- people who are severely-obese, and people who are immunocompromised and/or have underlying medical conditions.

People with disabilities can have underlying medical conditions such as cystic fibrosis or genetic disorders that may confound or divert focus from the predominant COVID-19 issue at hand.

Medical professionals to understand characteristics of people who are different can be especially helpful such as using a one-page profile. Communication preferences as well as the need to be propped up to enable a cough, can be pivotal pieces of information in emergency events. Research has shown that there are other barriers, that -- there are barriers other than medical conditions for people with disabilities, who seek support during emergencies.

We know about these, in our network. There is communication, housing, transportation, socioeconomic status, and eventually, reinstating natural supports, upon returning to the home environment.

The COVID-19 pandemic has brought other barriers to the forefront.

Some people with cognitive disabilities may have difficulty understanding the need for social distancing, and the need for constant hand-washing and hypercleanliness, some may not understand why or have sensory barriers for the use of a face mask.

Sometimes raising an arm to cover one's mouth and nose for a sneeze is not always doable.

I spoke with a mom on Monday whose son was having a hard time not going out to eat anymore. His favorite social activity.

He understood why, he just wasn't happy about it.

And I know many of us are going through that same challenge.

Now, I'm going to recap what we've heard. So we've heard from 12 centers and one ex officio.

Beth Potter, out of Kentucky, talked about the use of universal design learning to -- to ease the transition to virtual events.

Other kind of UDL presentations including the use of plain language that Bill Gavena touched on, and using visual supports and stories shared by Elizabeth Turner. [Electronic tone] related to UDL is the idea of taking known and accepted ways of doing things, and providing a new perspective or a new way to do it.

The use of DISCORD for social engagement was supercool to learn about and I can't wait, to use it at my center that Scott N. Mullins talked about and a link in the chat that had a how to. Sign up for that. Telehealth and virtual adaptations by Andrea Caoili at the center for START. That center has a ton of resources from their Web page, fantastic. Strategies of transition from in class trainings to virtual that Colleen McLaughlin shared and also, Colleen, thanks to

the shoutout for DSPs, I think we all feel that way, and sometimes we forget to say it out loud.

Staying socially-involved while distancing that Larissa Yoshino shared. And also partnering with their health department, you know, that can implement systemic change, which is really powerful.

And then sharing the involvement and leadership with the statewide disability task force, Dr. Laura Stough, and advising the emergency management office in Texas, on disability concerns and issues.

Another systemic change wave.

Dr. Amy Sharp: A range of topics, including Bill Gaventa, shared a resource list that is audience specific as well as really interesting and cool stuff, shared by Linda and Tara, the flip book looked great. A summary of rural pandemic experiences, with the use of data that Catherine Ipsen shared -- that's really powerful, and I'm going to go look at the two surveys that you shared. Puerto Rico -- gosh, Carol, Puerto Rico's unique response activities to a uniquely-constant disaster environment.

You just can't get a break down there. And I'm sorry, I did not even hear about the earthquake.

And then.... resources, and trainings and then the crisis task force, that Andrea shared at the Center for START also another way for systemic change, and Erica Coleman talked about advocacy and awareness on healthcare discrimination, and tools to help people with disabilities self-advocate when they get into an emergency situation.

Really powerful stuff.

So what I'm going to do now is turn it over to Meagan Orsag, who has

been monitoring the chat, and she is going to facilitate Q&A! Meagan, take it away.

>> Meagan Orsag: (Returning), thank you, Amy, and thank you, Laura, for serving as facilitators, again, I just want to echo, and just praise our presenters and just thank them for their time and all of the work that they've been doing.

I don't think we could have gotten more experienced robust group of -- of experts here with us today, and so I'm excited to be moving forward with a question-and answers portion. I will go through the chat, and I will read out the questions.

Once I read out a question, I am going to mute myself. And -- ask the presenters if this question pertains to you, or if you feel like you would like to respond -- I'm not going to call on individuals, to respond, so if you feel like this is a question that you are able to answer, that's directed to you -- if you would, please, take the Podium, and answer the question.

Meagan Orsag: I do also want to call attention, to the chat box, and that there are several of you, who have shared some excellent resources, and links as well. So I would definitely encourage you to scroll through the chat function and look through some of those -- those links and those resources, and save those as we move along.

So the first question, that we had pertaining to the presentations, was from Cathy Epperson and she says I am looking for a document that explains what COVID-19 is, and how to deal with it.

I think Larissa from Oregon health and science institute mentioned a document on this. We work with individuals that really do not understand the impact of COVID-19.

If we could have a response to that.

>> Larissa Yoshino: This is Larissa from Oregon, I commented in the chat with a link to our page, but similar to the voiceover video presentation that I shared on staying socially-engaged: We did one that is kind of your basic what is COVID? And what does it mean? And how does it affect you? And a little bit about healthcare rights.

So that presentation, is also available, on our page, alongside the one I presented.

(Pause).

>> Meagan Orsag: Thank you so much.

>> Dr. Salas-Pagan: This is Carol, also, the -- the -- Hi, the START from -- Developmental Disability Council in Vermont, they also did -- COVID-19 information by and for people with disabilities.

I will forward that to Meagan, and we translated it into Spanish so she could distribute it to -- it's, like, an eight-page handout. Okay?

(Dr. Salas-Pagan).

>> Meagan Orsag: Thank you, so much Carol, really happy to disseminate that too, if you e-mail that to us...

>> Hi, Cathy this is --

[SIMULTANEOUS SPEAKERS]

>> That there is a great resource for people with cognitive disabilities.

From the green mountain self-advocates, and that is -- I put a link in the chat box (Dr. Laura Stough) it's very well-done!

>> Meagan Orsag: Thank you, Laura!

Okay. I'm going to move on to the next QUESTION:

Christine's question, has anyone created visuals for nasal swab testing?

(A pause)

>> Elizabeth Turner: We at Vanderbilt haven't. But when I saw that, I immediately e-mailed my coworkers and asked them about it, if it's something that we could do. So thank you for the idea!

>> Meagan Orsag: Yeah, thank you, everybody! I think that's something that we can certainly look towards. If someone in the network has that, if maybe share that with our council, with the emergency preparedness SIG and we could disseminates that. The next question is from Andrea:

And I believe, it was answered in the chat function, she asked I'm very interested in learning more about DISCORD, I'm wondering if you noticed any safety issues with the app, and how you have helped people/parents/families address Internet safety for those using the app.

(People typing in chat box).

>> Scott N. Mullins: I'm just answer that real quickly. But one of the best things about DISCORD is you can be able to protect your privacy because you get to go on there, create your account, but the groups you set up to be a part of something, those are private groups. You can only access those groups until you're invited, or you become friends with someone that's a part of it, that goes ahead and invites you. But you can't just -- no one can just get on DISCORD

and come to our programs' events and everything, they have to invite them to be able to do so.

Meagan Orsag: Thank you, Scott. Andrea Larissa, and Cathy, you-all shared some great resources, I'm scrolling through the chat function now!

And helping to answer some of the questions, Laura, you shared a great resource.

Looks like plain-language information for people with disabilities.

Christine, mentioned, I would love to hear ideas to organize all of the content and resources for our families, and professionals.

Would anyone like to speak to -- Christine, I think you bring up such a great point, I think we all feel like we've inundated with information on LISTSERVs resource lists social media, e-mails. Does anyone have any hints or good examples of how you're.... organizing some of these -- these -- this content?

Or even professionals?

>> Dr. Laura Stough: Well, Linda Rammler earlier talked about her resource list and the way that they've organized it at the university of Connecticut, is -- be users. So resources for people with disabilities, resources for direct-support personnel.

Here at Texas A & M on our project Web site at RUDD.TAMU.edu. We organized by state, local, federal, and international.

And so it's always hard to organize this information, and these resource lists, but those are two ways that I have seen different organizations organize them, is by user, or by geographical spread. (Dr. Laura Stough).

>> Larissa Yoshino: This is Larissa from Oregon. One of the ways we've tried to sort out the enormous amount of information, is in to the type of



resource, so we have videos. Some links -- or some information about webinars that we've put on, just plain-language resources; and then, I think, state and federal -- but a little more towards the type of medium, I guess.

(A pause), Meagan Orsag: Thank you, Larissa, I think I've seen several of you sharing some resource links in the chat function as well. Amy Sharp, I see one from your Center.

Thank you, so much, for that.

Let's see...

Let me scroll through these.

Beth Potter shared her link and information, thank you, Beth!

Meagan Orsag: Susanna Miller-Raines, shared resources that are in plain language, thank you so much for sharing that!

We had a few questions, on whether this -- we're going to be creating a -- basically a one-pager, of some of these documents, and is that something that you-all are interested in? I think that's certainly something our council, in collaboration with the emergency preparedness SIG would be happy to do. I know AUCD has a running list of resources, so I would certainly work with Anna on that, if this is something that you're interested in.

Meagan Orsag: (Continuing) Doris asked, do these resources have a picture -- that are easy to understand for print out. Doris are you referring to the presentations or are is there a specific presentation you're interested in as far as a picture in plain language, for a printout?

While we're waiting for that. I'm going to move on to a couple of others.

Amy Sharp, thanks Anna, thank you so much Anna, we couldn't have done this without you!

Let's see Linda commented that people -- Connecticut has been using Zoom not for just board meetings and ongoing advocacy trainings but now has a weekly karaoke group. That's fabulous. I think something we've discussed within our own center, and especially with some of the our students in or post secondary program is they're missing that social interaction; and so, I love their presentation of hosting events, that are social events while we're social distancing. And I think that's so powerful.

And, like, online book clubs, and karaoke, just making sure people feel connected to each other, I think is so important during this time. Laura shared her resource. Susanna mentioned they have a Google drive with resources, Georgia-specific and some national.

Linda mentioned that there is going to be a YouTube available soon.

Okay Susanna, dressed the resources are easy to read and have images, SARTAC, Yvette says Zoom karaoke sounds great for our clients, that's great. Linda shared an illustrates story on her Web site. Fabulous.

And Christine agreed a UCEDD curated list would be awesome to share out.

Okay. I think that's something we can certainly work on.

That is... all I see for questions, right now.

There is a lot going on in the chat function, thank you, guys for your interaction and your engagement.

At this time.

Laura, and Amy, is there anything else you would like to share out, before we close?

>> Amy Sharp: And I would -- sitting here, reflecting on every -- I

think -- every UCEDD has a resource page, and every UCEDD is developing resources, and sometimes we're duplicating efforts, and sometimes we're, you know, creating new, and unique resources.

And I'm wondering, if there is a way, where we could -- I don't know what it would look like -- if we could come together so that we're not duplicating efforts, but that we could share it all. And I don't know the answer to that question.

(Pause).

>> Andrea... --

>> Go ahead.

>> Andrea: I was just going to say that I think that is a really important question to ask because, I think that, while we all have similar missions, across our UCEDDs, there are certain pockets of particular expertise, and it would be really great to be able to leverage that. (Andrea Caoili) so I think it is a big question, and a really important one to try to tackle, I think, because one thing that I think we've all realized, is that, this pandemic, this COVID-19 pandemic, is going to impact how we operate for quite some time.

So, I -- I think that things are going to have to change, and we should -- we should definitely consider it. So thanks for bringing that up.

>> Laura:. Yes, and in listening to these presentations, you know, there is much that we're doing that is overlapping, and yet as has been said, there is pockets of expertise.

So we have people in our network that have unique knowledge, and

contributions.

And tapping into that could be really powerful, as well as, you know, just pulling together all of these different resources, and linking that we have identified.

Individually.

(Laura Stough).

Meagan Orsag: Thank you, Laura, yes, and this is something that our council has discussed. The replication of resources, and how communication is it handled. How is information being shared. Who is creating what? And where is that located and shared? And making sure that -- you know, -- when -- are things accessible? These are certainly conversations we've had as a council, and so I really appreciate you bringing that to the table, Amy.

Yes, Jennifer agrees, central resource center, with local information. Locally.

Susanna, I think we leverage all that we have. And we are a network for reason, and there is so much expertise we can share with each other. Absolutely, and I think this webinar has certainly highlighted this.

Yes. Bill Gaventa -- Amy seems like your question, about bringing this all together should involve a conversation with the disability and public healthing staff at AUCD, and even broader the APHA section on disability. Don Lollar is a good contact as well as others, thank you, Catherine Ipsen: It seems like folks need to share their intentions to develop information as well, because in a time limited scope such as COVID-19, many efforts are happening simultaneously -- yes! Yes, and I think with our council too we've discussed, you know, what are some of the lessons learned, in these past few months,

since COVID -- how did we respond, as a network, who's being called to do what work? How are we sharing that as well -- I think those are some important questions to ask ourselves.

All right. Well, if Laura, and Amy, if you-all have nothing else you want to share out, I would like to take another moment, just to thank our presenters, Beth, Bill, Elizabeth, Larissa, Scott Linda, Catherine Ipsen, Carol, Andrea, Erica, Colleen, and, of course, Laura, and Amy -- we just want to thank you, guys so much for jumping on and preparing for this presentation! We want to thank you, for sharing your expertise, and your time with us today.

We --

>> Meagan?

>> Meagan Orsag: Yes.

>> Dr. Amy Sharp: We owe you a great deal of thanks as well for organizing and facilitating Q&A!

>> Meagan Orsag: (Laughing), I'm not sure I did that great of a job, but thank you, guys, I just -- I really appreciate everyone's comments, and.

[LAUGHTER]

>> Meagan Orsag: And I just -- um... I just have been led so well by this network, and I'm so honored to be in the presence of all of you, and truly, the group that we've pulled together, today, I'm just so grateful, for your time. I know you're incredibly busy, and just to see the work you're doing in our network and in our communities, what perfect hands, our communities are in right now.

So I can't sing you praises enough.

We will be doing some work as a council to put together your resources. We'll definitely put together your presentation and share that out.

Meagan Orsag: And then I would love to try to work on topic areas, the Center, and then a link to your information, so we can share that out. So, again, thank you, guys so much, for being on here. Anna, thank you for facilitating! We brought you a -- a big challenge, but this went great. And I'm just so appreciative of your time. Thank you, for all the attendees who joined us today.

We wish you all the best, please reach out to us, if you have any questions or comments.

Again, what an honor to be in this Network, with all of you. Amy, and Laura, I'm so proud to be from Texas, and working with you guys. So thank you, guys for facilitating today!

>> En masse: Thank you.

>> And thank you, Amy!

>> Anna Costalas: Thank you, everyone, please take a moment to fill out the survey. Be well! Stay healthy, and we'll talk to you soon....

(1:12:16 p.m.)