

AUCD Public Health Webinar  
Interactive Webinar  
Thursday, April 30, 2020  
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Remote CART

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COVID-19 public health webinar series will start at 4:00 p.m. ET

>> Hello, everyone. And welcome to the AUCD network webinar series on people with disabilities and COVID-19. Today is the fourth, also the last of our four webinars. Today's webinar will provide advice on your questions about COVID-19 that we have collected over the last three sessions, as well as the questions you may ask us today. We compile -- 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 and developmental disabilities and I am the chair of AUCD special health interest group. Together with Dr. Adriane Griffen, I'm one of the facilitators of this webinar.

First we would like to thank you for joining us today. We know that everyone is always very busy during these rather challenging times and we appreciate you taking the time to be with us. 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, please submit your questions at any point during the presentation, or after all presentations have concluded via the chat box on your screen. You may send a question or comment in the chat box to the whole audience or privately to the staff or presenters. Please keep chatter in the chat box to a minimum and prioritize questions. Since we have many people attend, too much chatter in the chat box clogs it. We will compile your questions throughout the webinar and address it at the end via our discussions and our question-and-answer facilitator. Please note we may not be able to address every question individually, and that we may have to combine some of your questions. This 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 the close of the webinar. We invite you to provide feedback on this webinar and provide suggestions for future topics.

So why are we doing this webinar series? Well, 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 information useful.

Now I would like to welcome today's distinguished panel speakers, and thank them very much for agreeing to present today. They are from many different agencies and organizations. And have a wide variety of expertise. Our panelists today include Dr. Georgina Peacock she's a physician forth CDC. Miss Tami Theiler from the federal emergency management agency, FEMA, works with the COVID-19 response team. Miss Maribel Hernandez from the center for excellence and developmental disabilities at the UC Davis mine institute also a caregiver of an adult with disabilities. Mr. Max Hernandez, and Dr. Laura Stough who is at Texas A & M university. In addition to our great speakers, we also have invited some fantastic discussants. Hector Ramirez and Carolyn Chang who practices family law in Burlington county in New Jersey. She has many talented and has mayor and committeewoman for the township of Westamton, New Jersey.

The facilitator will be me today and I will help move questions along after the presenters have finished and the discussants have shared their thoughts. I will now pass the microphone on to Dr. Adriane Griffen who will get us started with a few words about public health.

>> Thank you, Dr. Riddle. Appreciate it. Welcome everyone. We wanted to take a couple minutes at the beginning to review how we define public health. We recognize that public health is a new term for some, and you've heard it quite a lot over the last few weeks. So what is it, exactly? Public health promotes and protects health of people in our community, so that's basically everywhere. It's where you live, learn, work and play. Public health also prevents people from getting sick or injured as well as promotes healthy behavior and encourages well in. It's also a blend of science as well as an art. So that's why the different guidances sometimes are evolving. We're learning as we go.

AUCD also sees public health as being for everyone. For my friends on Twitter we do the hashtag #PHis4everyone.

For managing change and thinking creatively about how to do things differently. Public health is for everyone is our motto and framework for AUCD's national center on disability and public health.

We also want to give a shout out to partners joining us today to invite you to work with us. AUCD works in every state and territory and we have a presence through three different kinds of members and I want to review what these acronyms stand for. UCEDDS are university centers for excellence and as well as our intellectual and disability development research centers. Together we advance policies and practices that improve health, education, social and economic well-being of all people with developmental and other disabilities as well as their families and their communities. So thanks for giving me just a moment of the shared virtual podium here to share our thoughts on how we apply public health.

Next it's my pleasure to turn the virtual stage over to Dr. Georgina Peacock on how the community can continue to access information. Georgina?

>> Thank you. Are you able to -- do you want me to advance the slides?

>> I'm happy to if you want to say next slide.

>> It looks like I can do that. I am glad to be back here. I'm glad to bring you some updates from CDC.

So the first update I would like to share with you is that there were some updates made to symptoms that are provided on the website related to coronavirus. As you -- I think initially we had just a few symptoms. Cough, fever, and shortness of breath and you'll see other symptoms have been included here on the CDC website. And this is just an example of some of the updates that we make to the CDC website as we look at the data and as we

understand more about COVID-19.

I also wanted to alert you to the fact that on the CDC website there is a self-checker. This will take you through a decision tree about what type of medical care you may need to seek if you are having certain symptoms. So I encourage you to go to CDC.gov. On the first page you'll see the coronavirus link and then you'll find this self-checker on there and can take yourself through that. And I think it's a helpful guide for people to use. And we know that many people have used that already to help make decisions for themselves.

The other update that I would like you to be aware of is that we have posted some information about children and youth with special healthcare needs. So that is a frequently asked question that is available, as well as some updates related to people that have asthma.

And then I would like to share that we have also some guidance here listed related to people with disabilities with direct support providers. And you know, essentially we provide some guidance of what people with disabilities can do, when they're working with their direct support provider in order to prevent either one of them, but in particular the person with disabilities from having exposure or undue exposure to COVID-19. And you can see that all of these -- I think Adriane will be able to provide these slides to you afterwards, and there's hyperlinks in all of them that will take you to the CDC web pages.

This is some information that might be helpful. And we wanted to talk a little bit more on the use of personal protective equipment. There is guidance on how to -- personal protective equipment is intended for patients with confirmed or suspected COVID-19 or people who are caring for those patients. There's guidance on how to do this, and I think this is a reminder to let you know that cloth face coverings are not PPE. When we talk about cloth face coverings, these are meant to protect other people in case you're infected. So if the reason why there's recommendations that people wear cloth face coverings is because sometimes we know people may have COVID-19 and they not be aware. So that's why there is a recommendation right now in public settings for people to wear cloth face coverings.

When -- and so I've just provided some examples of the pictures and the instructions that are there on the CDC website.

And then just a reminder that everybody can practice -- sorry. Can practice everyday preventative actions, including cleaning your hands often, making sure when you wash your hands you wash with soap and water or you use hand sanitizer that has at least 60% alcohol. Avoid close contact with people who are sick. Use some protection if you are caring for somebody who is sick. Stay home as much as possible, especially if you are at higher risk for COVID-19. Avoid touching your face, eyes, nose or high-touch surfaces as much as possible. Use a cloth face covering as I talked about before, and clean and disinfect those surfaces that are often used.

And so with that, those were just the updates that I wanted to provide that have been made to the CDC website. Thank you.

>> Thank you so much, Georgina. That was wonderful.

Next up on our virtual stage is Tammy and I want to make sure I'm saying your last name right. Help me out here. Is the Theiler. ?

>> It's pronounced like Tyler. It's all good. Hi. I'm Tami Theiler. I am a volunteer agency liaison with FEMA and we are active in response to the pandemic. And before -- okay. There's my first slide. Before I go to the first slide, I just wanted to take a minute to provide a quick update about what FEMA is doing. So right now, as you are more than likely aware, there is a nationwide emergency declaration for COVID-19 for all 50 states, 5 territories and 56 tribal nations. And what that means is that those entities are eligible to apply for FEMA public assistance in order to support executing emergency protective measures.

In addition, ten states have been authorized to carry out crisis counseling programs for

COVID-19. And basically what this is is FEMA provides a grant to the state which administers the program to ensure the safety of the clients and the counselors. The sessions are being conducted virtually. What I wanted to highlight is that services are available in ASL and multiple languages.

The last update is that several task forces have been established to focus on areas of concentration among them community-based testing, security, casualty management and supply chain stabilization.

On the first slide here I just wanted to talk about a little bit about what a voluntary agency liaison is. Because you may not be familiar with us. So we work to foster partnerships to support the delivery of services to address the related needs. In terms of this response, we are coordinating with both voluntary organizations and federal agencies. Among these are send relief, the salvation army, American Red Cross, the department of housing and urban development, and the U.S. department of agriculture and small business administration. And I just wanted to take a second. On the slide here there are three pictures of our partners in action. The first picture on the top is a group called relief in providing food in Manhattan. The picture below that is staff from an organization called IT disaster response center. Providing IT equipment to nonprofit organizations to help them support their communities. And the picture on the right is a group called operation barbecue relief. It's a group in Kansas passing out meals. And you can see that to maintain social distance, they're doing the delivery of the meals via drive-through. And that's something that's become common among the volunteer agency partners to adapt to social distancing.

So the voluntary agency liaison are also a resource for understanding FEMA programs and policy. For this response one way we're doing that is three times a week we host a coordination call for our partners to provide updates in this particular area of the response. We are also producing a daily report that provides situational updates and highlights partner activity. And I just wanted to mention that on our call tomorrow afternoon we are going to be featuring a representative from the HHS, administration for community living. In addition to those things we serve on several task forces that I mentioned earlier.

The best way to get ahold of us is to use the email address that is on the slide. And it is [VAL-Team@fema.dhs.gov](mailto:VAL-Team@fema.dhs.gov). That is our main inbox, and there are nine of us at headquarters. And at least one VAL in each of the ten FEMA regions. And specific area office. And we are happy to connect you with them.

Next slide, please?

Thanks. So we had a question about the regional disability integration specialists. And this team is out of the FEMA office of disability integration coordination. And as you can see on the slide, they advise regional leadership on issues impacting people with disabilities across the states, tribes and territories. They serve as liaisons between regional offices and the office of disability integration and coordination, which is at FEMA headquarters. And they engage in education and outreach on disability issues with state, local, tribal and territorial and NGO and private sector partners. So their job is basically to provide education to FEMA's partners regarding the rights of persons with disabilities and access and functional needs. They're there to help us not only make sure that we're abiding by the law, but that we're doing the right thing.

During this response, the team has helped create a fact sheet on eligibility of accessible communication expenditures under public assistance. Working with groups providing communication services to get reimbursed from the government for working those services.

They're also hosting a daily coordination call with the regional disability integration specialists. And they have a weekly coordination call with FEMA interagency partners like HHS and HUD. So you can see there's some overlap between the partners that we work with. So we work in close coordination, but at different purposes. They are there to make

sure that we are abiding by the law and doing the right thing. Next slide?

With the question about virtual support, and I wanted to highlight four different organizations. The disaster distress help line which is the first one, is the nation's only hotline dedicated to providing 24/7, 365 crisis counseling and emotional support to first responders or anybody in the U.S. experiencing distress related to natural or human caused disasters. The hotline is answered by train counselors from a national network of independently operated crisis centers who offer supportive counseling. Including information on common stress reactions and healthy coping, as well as referral to local disaster-related resources for follow-up care and support.

One thing I really want you to know is that the disaster distress help line is a sub network of the national suicide prevention life line. So they have funding from SAMHSA.

The next is the national domestic violence hotline which provides support to help victims to live lives free of abuse 24/7, 365. They have highly trained advocates to offer compassionate support crisis intervention information, educational services, and referral services in more than 200 languages.

The next group is the National Alliance on Mental Illness also known as NAMI it's the largest grassroots mental health organization dedicated to helping Americans affected by mental illness. They provide support, education, and advocacy at the national, state, and local levels. Their programs are offered at no cost, and they include peer support groups, family support groups, classes, and community outreach. And I wanted to mention that some of those groups are being conducted virtually.

Then I wanted to mention MAVI. If you are on the line or from Puerto Rico or work in Puerto Rico, MAVI offers support services and skills training to help those living with disabilities maintain their independence. And this includes the centers for independent living that are on the island.

Next slide, please? And I know my time is running short. So I will go quickly and stand by for questions.

There was a question regarding finding support for those who might be in need of food. I wanted to point out feeding America's foodbank locator. If you go to that link you can enter your zip code and it will direct you to the closest food bank. And it will allow you to find food in your area.

Food finder is a website, but they also have an app where you can log in and enter their zip code and find the nearest locations that are distributing food and serving meals. And some of the information that's provided includes address, phone number, and dates and times of service.

The next is a link to the USDA assistance available during the pandemic. A couple of noteworthy things is the pandemic EBT. The food and nutrition service is allowing states to provide benefits to children who normally receive free or reduced lunch that don't normally receive SNAP. There's an online purchasing pilot for beneficiaries of SNAP where they can go and order and pay for groceries online through the same stores that everybody else can.

And then the next slide?

There was a question about information resources. So what I've included here is the coronavirus website. This is the government's main hub for information regarding the pandemic. It provides the most up-to-date resources with links to all the responding agencies for additional details. Then there is the FEMA rumor control page. Our socialist main crowd sourcing and affairs team are monitoring the media to identify possible misinformation. When a trend is spotted, they work together to distinguish rumor from fact and post that on FEMA.gov. Then we have 211, which covers 95% of the nation. And this is an information and referral service and you can either go to the website and enter your zip code, or dial 211 from your phone to get assistance finding food, paying housing bills or other

essential services. The last link on that slide is National VOAD and they are a coalition of voluntary organizations that are active in disaster response and recovery. They're a great source on the work those organizations are performing. They're also an excellent place to start if you are looking to support the response through a donation or volunteering.

Next slide, please?

Great. I do not have anything else. Thank you so much for your time.

>> Thank you, Tami. Appreciate you sharing these wonderful resources. This is Adriane. While I have the microphone, I want to remind everyone that you can download the presentation slides there's a pod below the chat where you can do so and you will also get copies in the link afterwards as well. Thanks again, Tami. Next we have Maribel Hernandez and max Hernandez sharing their perspectives on dealing with COVID-19 both from a family perspective as well as living with a young adult with a disability. So I believe Maribel your slides are up first so I will pass the virtual stage over to you.

>> Thank you, good afternoon. My name is Maribel Hernandez. I have two sons. Max who is 19 and Chris who is 17. They're both on the spectrum of autism. I'm a full-time mom. I'm working full-time. And I have to work from home and I have to keep -- I mean, two partners. And you know, staying at home.

So I like to share with you what is helping me to feel safe and confident during this hard time.

We don't know what it's coming up, what's to expect. This feeling is not new for me. I think when you have a child with disability, it's always like that. I remember elementary school with Chris, just a roller coaster. Great day, great day because you don't know what to expect because next day he's going to hit. So this feeling is not new for my family. Don't know where to go, what's next. So the priorities for my family has always been details. Details and after you know you take care of your health, because I always feel like that. If they have a headache, they're not ready to learn. When I have a headache, I don't want to listen, I don't want to learn. I don't have you know the energy to do things. So the first thing is to be health and it's very important in this time. After that is the behavior. Once we get in the lockout, Chris had a crisis and he just had to take it calm. You need to have peace, resolve and help your child to go through this hard time that's not just for them, for all the people it's hard. Help with the behave and then all these things to do with the school.

We have to take that time. At this time it not very important for me. Chris is still at school and is taking classes and he has to look in and check that he's present every day. I just put that on the side and we try to do the best that we could. We are not really focusing on that. We are focusing on the health, the peace, and of course social time with them, that's the most important part. Because the school does social time, that's their only opportunity to be social. I mean Chris has a social group, but the real time when they're social, that's when they go to school. And they don't have that time now. So we have to do something at home. We can see in the picture. A puzzle, that's social time, doing activities as a family. Exercising together. Of course the mealtime. And taking that time, especially for Chris. Because he loves to be in his room. So what we do is just organize the day. Before we used to have a schedule, because we have school, we have time for the meal, we have to cover a schedule. At this point we go through a checklist. You can see in the other picture, we have a checklist. Very important. Medications, brushing his teeth. He needs to practice piano. Every family has priorities and things that must-do, like the medication. That's a big thing so that's what we have on this sign on our checklist. Just the things that we should do. Trying to organize our day the best that we could.

I'm being careful on what they're looking at and be careful what they listen. Because that's scary. There is a lot of information. And when they have access to the Internet and a bunch of information, it's just scary. So I'm taking the time to limit that information and just make

sure that all that overwhelming information is not touching them. Because they're 17 and 19. I've always been afraid for them to get anxious or to get depressed. And so that's why it's very important for me that they don't have access to misinformation or too much information about what's going on.

And the other part is this part with the school and the services. Chris has services, a social group and actually he has more services now than before. And he's attending to the school. So I think it's very important to have -- you know, to be careful with the expectations with the school and with services. And with this going on, this Chris. He's 17. So how I see this time, this new experience with his services and the school, it's like an opportunity to learn. This is being an opportunity to learn from Chris. Because for real, I have never had the time to see what he's able to do at the computer. I have never seen what he's able to do in math. And this is a great opportunity to learn about my own child. And to learn about all this new systems with the school. And that's why I'm being very considerate with the teacher. Because this is new for him too. All this virtual learning, it's new for all of us. So we have to -- they are people too, they're learning. We have to learn together and we have to be open that -- like, I do the mistake. Chris supposed to have Zoom meeting every Tuesday. He has missed that the last two weeks. We don't pressure about that. The same way his teacher if he does not answer the phone right away, I only have one. I only have Chris. This guy, poor guy, he has 18 more kids to help. I know it's his job, but for real, that's overwhelming. And I think he is doing his best and I know because I have a wonderful communication with him. And that's what we need do. Because if we don't communicate, they don't know what we are really concerned about. And just communicate whether it's the best way to start or help.

These times are very special. Like I share with you. Nobody knows what's next. And nobody knows what to expect. Let's take your time to learn about the kids and let's take the time to take care of them and be understanding that with the services, probably there's new people or less people, less staff or more staff, or new staff that we need to have that communication and share the things that our child likes or dislikes. Our child is learning to get on the Zoom too or on virtual -- they're learning too. So let's have this -- let's slow down. Let's enjoy what we are doing, and it's going to be easier to learn.

What has been helping in my family, like I say this feeling don't know what is next, that's not new. And we always identified priorities. Like I say health, behavior, and learning come later. That with that we have in this time a very flexible schedule. Before we have a very rigid schedule, because we have to run from school to the service to time to eat and go back to work and all these things, a crazy schedule we used to have and now we have a very flexible schedule, it's actually just a checklist. And remove the stress. Have a plan. What is going to happen if one of us get sick. This is something that we have done years ago. We have this binder with information, because I have to. I have Max and Chris. So we have this binder where the last IEP, what services are they serving, what are the schedule, what is the medication, who is the doctor, who is the contact person. So we have all that information in their binders. So they're ready to go. In emergency we have talk with their friends and have a plan in case I get sick or one of my kids gets sick.

This is a time with a big change. There's nothing like that before. We feel overwhelmed and it's just a big change. Our normality has changed with a big change. But this is not the right time to recreate. This is not the right time to look for new services. This is the time to be open to the collaboration and be nice with -- we need to understand we all have stress. This situation is new for all of us. And we all are learning together. Like all the times, very important to take care of yourself. We need to find what we like to do, what is relaxing for us, how to put away ourselves from the kids, from the work, from the cleaning the house, from all the things that we have to do every day, we need to find this time to take care of ourselves.

It's very important to keep this. This is a really good time to talk with friends. Most friends probably they stay at home too and we can call and have that time, have that connection that will help us to have that time for ourselves. And it very important to ask your kids how they feel. Like I share before, I'm always afraid that they get anxiety or they get depression. So it's very important in this time to be open to those feelings and recognize where they are and take the time to ask them how they feel if they -- if they get nervous about something -- find help. I know that probably you think all those kids are very easy. Yeah, they're very easy because I know my kids. And I know where to look for help and I always seen before with a great team. Because I like to share where we really are. What are our needs and what I want to see and how I can help the professionals support the services for my kids.

My kids were diagnosed with autism I start to learn about analysis behavior apply and that's been helpful to my whole life. I have 18 years practicing analysis behavior applied and this has changed our lives. That's what we do every day. And it's very helpful. Time now, schedule, all the visuals. That's been wonderful and I put the resources in Spanish. I know there's a bunch of resources in English but I wanted to share the resources in Spanish. If you enter the UC Davis website you'll find that the autism education training in English and Spanish and it's based on ADA and it's a wonderful way to start to help your child, to understand the behaviors and see how if you can work with the behaviors. So gracias.

>> De nada. That was wonderful. Thank you, Maribel. We appreciate you.

Next, we can turn the virtual podium over to Max to share your perspective.

>> Hello. I'm Max Rivera. I'm a first-year college student and I am 19 years old. But unfortunately due to the coronavirus conspiracy, I'm not able to go to the consumer's river college because I'm quarantined at my home. So I would like to share to you what would be the best perspective to do when you're trying to be safe at home.

Now what is COVID-19? We all know that COVID-19 is a very contagious virus. But if you were infected by it, we would feel like we can't be able to breathe or maybe cough a tiny bit of blood from our mouths. Out of all this conspiracy I feel very nervous, because if you show no sign of sickness you could easily get infected by the COVID virus.

Well, what we need to know is that you must be careful with people that looked healthy, because they may look healthy on the outside, but on the inside they could already have the virus whether they may know it or not.

Well, at this time I would say that these times are the very best days of my life. Because college days have started for me, I didn't have a lot of social life, because when I get to school on Uber, not much of the Uber drivers were talking to me when I got there. And when I got back from college by train, there were much people inside the train or some other people prefer texting inside the train. And whenever I get home, the only company I have were my two pet dogs. Oswald and Gizmo. I have more social time with my family. For example, my little brother Chris Rivera. I usually like to teach him how to wash dishes, to make sure this doesn't have a single speck of spots or bowls on the plates. And I have more social time with my mother whenever I exercise with her when we're trying to lose some weight. We like to talk about jokes or something we wanted to tell each other. And we usually do that during mealtimes, whether it's breakfast, lunch or dinner. And the best parts of when we're talking is during the weekends when we're doing family activities. Whether it's whether it's doing puzzles together from a puzzle board or when we usually like to watch movies, whether they're funny, entertaining, or historical. And we usually like to talk about each other when we were looking through family photos to see how the past was.

And the time that we spend we usually get hungry. So during cooking time we usually like to make very delicious meals that would beg our mouths to eat that delicious dish.

Now I know that I can't go to consumers river college, but I do have a lot of free time. So I use that free time wisely. So I usually like to practice on driving tests on the computer and



read the driver's manual, because I am studying for my driver's test whenever this COVID is over. And beside that I usually do household chores, whether it's washing the dishes, doing laundries and fixing the bed.

Even I do it a little bit of sweeping.

Now, during the practice, and after practice on driving, I usually like to practice on my drawing, because one of my classes from college is an art class. And after the whole entire day of the week, I usually spend the rest of my free time watching the computer, watching TV, or simply playing video games. Which one of my favorite video games is Skylanders.

Now I know that this isn't the best time, but during this time you just have to be safe. Just try to enjoy your free time, whether it can be a bit bad outside, but you can try to entertain yourself. Help people at the house by doing chores or try to entertain them. I know that I don't check news often, but I do know that I can get sick, so I just to be careful and just be healthy. We all have flexible schedules due to the coronavirus, so we can just use our free time and have a flexible schedule. Just remember to be nice with yourself. Try your best. And don't pressure on your schedule. Just be safe. Make sure you're clean, and make sure you're safe at home. At Jim Carey would say, good afternoon, good evening, and good night. >> Thank you, Max. That was great. Appreciate your tips for maintaining good safety at home during these times. Appreciate you being here.

Next on the virtual stage we will have Dr. Laura Stough who will be addressing some of the other questions that came up during our webinar series. I'll pass the virtual microphone over to you, Laura.

>> Thank you, aid ran. Good afternoon. This is Laura Stough and I lead project REDD research education on disaster and disability here at the center of disability and development at Texas A and M university. I am also associate professor of psychology and faculty fellow also here at Texas A & A University. I also chair the emergency preparedness for AUCD so I'll be talking about connecting with members of the preparedness about lessons learned from disasters and some action steps we can take moving forward.

As a researcher, I see the current pandemic not only as a public health crisis, but as a disaster. And we as researchers talk about hazards. In the current scenario the hazard is the virus itself. It just happens to be a virus, not your typical tornado or hurricane.

The formal definition of a disaster is a hazard that seriously disrupts the functioning of society and causes widespread human, material, economic, or environmental losses. So I argue that the word disaster certainly does apply in the current pandemic.

So to begin with the conceptualization of pandemic as disaster, what you see here on the screen is an illustration of the disaster cycle and this conceptualization of disaster has been around since the 1930s and it's taken on different forms across time, but this is a pretty straightforward model that you see here.

It is a useful model, in thinking about the steps and activities taken before, during, and after disaster events. And classically the cycle involves the four phases that you see here, preparedness, response, recovery and mitigation. And I will say that there is limitations in taking phases too literally. Many activities will take place across multiple phases.

So here on the right side of the diagram with the phase preparedness, preparedness includes activities in anticipation of a hazard and actions that will lessen the impact of that hazard. In the case of COVID-19, it would have meant ensuring the supply chain face masks and other personal protective equipment, quarantining incoming travelers from high risk areas. Preparedness is what we do to lessen or even avoid the impact of a disaster.

Moving to the next phase, response.

The cycle conceptualizes the impact happening in between the preparedness phase and the response phase. And the response phase is what occurs during or immediately following the disaster. And those are actions you take to stabilize and present future -- further

damage.

So in implementing the self-protection measures that have been discussed earlier, we're being asked as individuals in effect to participate as part of the emergency response to this disaster. So during this phase, activities of emergency management and public health include monitoring the evolving situation, supplying hospitals with supplies and needed staff, and dealing with sick patients as well as the economic repercussions that we're currently seeing.

During the next phase of disaster, the recovery phase that we're looking forward to and planning for but not yet there, is the recovery phase. And so recovery occurs after immediate safety and survival needs have been taken care of. So in other disasters like tornadoes and hurricanes, this occurs after the hazard has passed. However, with COVID-19, the event is still unfolding. Unfortunately we're still having a large number of people hospitalized and dying during the crisis. So we're still concerned with immediate safety and survival needs. So we're still in that response phase. We're not quite -- we're not yet in the recovery phase. We know also one of our speakers talked about food banks and that's another sign that we're still in the response phase. Taking care of immediate survival needs.

The final phase that you hear is mitigation and activities taking place during the mitigation phase include those that will reduce the damaging effects of the future hazard. So mitigation effects would be strengthening our public health and medical systems, ensuring vaccines will be ongoing and able to be disseminated quickly and learning from lessons we see today, including incredible vulnerability of nursing homes and people with disabilities to health emergency. And that takes us full circle back to preparedness. So together with mitigation, these activities during the preparedness phase again then have to reduce the threat of disasters. The phrase being in currently is the response phase.

So those of you who are on the first webinar as part of a series, I shared this slide with you. And I believe that our network, our AUCD network is a part of, a potential part of the response to this pandemic. We have the capacity and connections to amplify the response to this pandemic by the disabilities community and I'll spend the rest of my presentation sharing some of the efforts we've mounted here at the center as well as digesting some con creed ideas for your own center.

Many of you have research lists like you'll see here. And a list of information and resources. This is a great tool for the disabilities community seeking additional information. This is our page when you visit our project REDD website. We also have not only COVID-19 information, we also have several resources that you heard from FEMA and CDC today, you have links to them, state resources and local resources. I want to encourage you if you don't have your own site or if you do have your own site to borrow from ours. We've been working diligently on it and of course update it for your own states. And I encourage you to maintain these lists, because then quickly populate it, modify it in the case of future disasters involving different kinds of hazards.

Second we want to connect people with disabilities and resources on your website. So that's really invaluable for people seeking additional information. And here you see that we have a notice here, people who are contacting us at our center in bold, we remind them, hey, if you need immediate emergency assistance, please call 911. That connects them to emergency management. If you're needing assistance for social services due to COVID-19, call 211. That's how here in Texas, and I think in many of your states there's a directory of social services. But we also include this. If you have access or accommodation needs related to the current COVID-19 situation, call your local office of emergency management. Or call your local city hall. This is a way that we let emergency management know what the needs are of people in the local community. And as a reminder, the way that emergency management is organized and enacted in this country is from the bottom up. That means

from the county or parish level and up to the state.

So if your local emergency management office doesn't know about a communications need or a transportation need or a durable medical equipment need in the context of this emergency, then they can't resolve it. So if they don't know about it, they can't help resolve it. They can't ask for assistance and maybe really importantly, they're not letting your state know that there's an unmet need in your community. So this is one idea of letting your people contacting your center how to go about this.

You can talk with your emergency management member who's part of your center to help you know if you should include the 211 information or even to create a directory of offices of emergency management on your website.

Also I would encourage you earlier, we heard from Tami Theiler from FEMA, and she was talking about your regional disability integration specialists. We're in the middle of a pandemic. Do you know who your regional disability integration specialist from FEMA is? If you don't, reach out to a member of your emergency management SIG and they'll connect you up. Those are incredible people to be connected with during this point in time.

Here's another method we use to connect the disability community and emergency management community. This is one of 43 county-specific sheets that we, along with the center on disability studies, at the university of Texas designed following hurricane Harvey. What we see here is for each county, the office of emergency management the council of government, which is one step up from your local official of emergency management, the center for independent living that serves that county, the educational service center that serves that county and the local IDD agency that serves that county. Because what we want is the entities to know who each other are at the county level. That's how emergency management works from the local level up. So these entities are connected and in communication they can work together in resolving problems at their local level or pushing them up to the local level with respect to the current COVID-19 crisis.

So this is one idea of what you can do on a county level, connect those resources and those players. I would add for COVID-19 your local public health organization or your local public health authority, that's particularly important in rural counties.

Third consider developing tools, materials, support that will further the work of public health and emergency management in a situation. Again I shared this chart with you in our first webinar. Some people with disabilities encounter barriers or inability to follow some current CDC guidelines for self-protection so we simply took those guidelines for self-protection, which are across the top of the chart, crossed them with five functional types on the left-hand side and within each box of the chart we list modifications and accommodations. To support implementation of this action. And then we shared this with our department head state health services. We also post this on our project REDD website. You are very welcome to borrow it, modify it, share it with your partners in public health.

You might also design and construct tools with other partners in your state. We have collaborated with our governor's office on persons with disabilities, the department of state health services, and the office of emergency management, develop an effective communications toolkit. This toolkit helps emergency personnel ensure that communication services address the functional and access needs of everybody, including people with disabilities in the community.

And so in this toolkit we detail how to use person-first language, plain language, multimodal communication, sign language interpreters during emergencies like the current pandemic. So we have in the toolkit over 80 pages of very concrete guidance and suggestions for emergency managers. And our department of emergency management has this toolkit on their website at [preparingtexas.org](http://preparingtexas.org). You can download it, share it with your state partners and consider modifying it for your own state.

Again developed in collaboration with our sister center at the University of Texas, the REDDy directory, Amy Sharp and I originally developed this in response to Hurricane Harvey with support from AUCD and ACL. And so when the coronavirus hit, we were able to take our REDDy directory, copy our template, rename it. You see at the top coronavirus resources, and then review which of our REDDy directory resources were also appropriate and able to be used in the current COVID-19 emergency. We're happy to share the tool with you and can send you the code. We just got the user's guide so you can create the only directory in your own state. But there is many other tools and services I'm aware of that the AUCD network is being really creative about in designing and providing to the disability community. Of course the people in our network who have been doing this for quite a long time are the members of the emergency management CID so I encourage you to contact them and see what kinds every tools, resources and handouts that they have developed.

So I will conclude here and again at some point this pandemic will pass and we're going to need to restart our research and our education and our programming that is currently suspended. So I want to say again that you and your work are really valued assets to the disability community. And when you take care of yourself, you are also taking care of the disability community. Because we need you as we move from response to recovery from this crisis.

Thank you again for all the work you're currently doing.

>> Thank you so much Laura. We appreciate you. I want to echo, yes. We do need each other in everything.

Next up we're going to turn it over to our discussants. Our first discussant is Hector Ramirez to disability Rights California. I would like you to share your thoughts, reflections and maybe a question or two for the speakers today

>> Thank you, gracias. I live -- with my mom and that's one of the ways I'm coping. I'm used to having my own space. I'm not used to sharing with so many people so this is hard to adjust. But just listening to the presentations were very, very intriguing and I think two thoughts came to mind. One around data collection and the other one of course coming back to the issue of access. In regards to data collection, especially as we heard from our CDC presenter and FEMA presenter, one of things that kept coming to mind is that we really need to start really having more of an effort, intentional effort, to start tracking the number of disability people who have died from COVID-19 and the reason for that we definitely are becoming aware of the hot zones that are occurring for people with disabilities tend to signal we already need that, seniors, people with underlying medical conditions made originally the two highest adverse groups and they still are, even across ethnic and cultural disparities.

But the reason why this information is also important is so that as we prepare to provide more response, and more services, we're able to not only tailor the interventions that are given to people so there's more accessibility, for folks to get tested and treated. Now for example in L. A. County where for the first time everybody is able to get tested, this is an important thing to track. As we move forward. Because we will be moving forward. We know that the issue of access is still something that is very challenges for a lot of folks, primarily not having access to safe spaces to practice physical distance or even having access to information. Just an incredible example of how, by utilizing accessible means and best practices and having our captioners and ASL interpreters is a really vital way to really communicate with those of us who are at higher risks.

Unfortunately that's something that still isn't happening in a very uniform way. So sense we do have a national pandemic sharing some best practice and reminding counties and cities and states that they need to provide accessible information in the form of sign language interpreters which are essential workers and captions workers which are essential workers and phone services for those that utilize that. Because that is a way that many of us

are only getting our information. Being at home, for many of us, this is a new thing. For others, those of us who have been in institutions before, this is a traumatic way of doing it. So not only do we have a COVID pandemic but I think we also now have a mental health pandemic and I think that's something that also needs to be addressed. So I was wondering if perhaps when somebody from the CDC or FEMA can perhaps address those questions or comments.

>> Thank you, Hector. I'm wondering if Georgina, are you still available? If you want to take that question? Or Tami, if you would like to. Either of you. Thank you.

I'm not hearing anyone on the microphone. I don't know Georgina if you are able to take the microphone and respond to the question.

>> This is Tami. Can you hear me now?

>> Let's go with you first since you have the microphone. Go ahead.

>> Tami Theiler: Sure. Regarding mental health, I absolutely agree that it's critical that we address it from the perspective of FEMA. That is why we offered the counseling crisis program. They are still getting up and running. But when they are, those will be trained counselors available virtually for anybody who wishes to call in. Again, I'll emphasize the disaster distress help line, which is already available 24/7. And if you are Deaf or hard of hearing and you need it, there's video relay available and there's TTY also available. We also have from national voluntary organizations active in disaster several groups that are out there performing what we refer to as emotional and spiritual care. Some of them are secular groups, and some of them are faith-based groups that have chaplains and things. And the Salvation Army has started a hotline that runs from 9:00 a.m. to 12:00 p.m. and I could put that number in the chat. I will say that unfortunately at this time, they are not set up to accommodate those who are Deaf or hard-of-hearing. Does that answer your question, Hector? Is that what you were looking for?

>> Thank you, yeah. I just, I think perhaps as we do our coordinated effort to address COVID-related issues, this is perhaps something that needs to be parallel, as far as services, emergency services. I think it really highlights the importance of just knowing how much people with disabilities are being directly impacted by this and how that is manifesting. I think that perhaps, I know it's a complicated issue, but if we had that information, then it could help us perhaps provide more of a unified response effort. But also kind of prepare -- because we are going to get through this. We are going to get through this. I know we are. And I think knowing how our disability community has been impacted by this is very important for that information.

>> This is Georgina. Sorry. I was talking -- I was connected but you couldn't hear me.

The other thing I wanted to share is that we are monitoring some of the -- we're monitoring some of the situation related to some of these negative impacts that you're talking about with the pandemic. For example, we're able to look at why people are going to the emergency room for things other than COVID-19 and what we are seeing is we have seen an increase of number of suicide attempts. We've seen an increase in the amount of people presenting for intimate -- intimate and domestic violence, as well as things related to substance use. So we're monitoring those things and will then provide that information back out so that people can act on that. You know, one of the things we do at CDC is we try to provide -- we try to provide the data that's out there and then bring it back.

In reference to monitoring what is happening related to people with disabilities in hospitalizations and deaths, we are working on that. It's in the case reporting forms that we ask states to fill out and send back in to CDC. There are challenges at the moment with getting full data back. Partly because there is so much work happening in health departments, that it's very, very challenging to complete all of these data forms and get them back in. But I would like to let you know that we are trying to address this issue in different

ways. We're starting to try to look at some of the administrative claims data sets and things like that to try to tell the story about what's happening to people with disabilities. But I also encourage -- we've got many I think researchers on the line, these are important things to communicate out and I think we should do this as a whole. We can all contribute to getting that information out there.

As far as work related to mental health, we also are doing a lot of this work around public health campaigns or sort of communication campaigns. A lot of this is being done through social media. And we are able to sort of monitor what people are saying related to coping, anxiety, stress, things like that, in specific populations. And then we are trying to produce communication products that will reach the populations that are exhibiting certain things that may need that type of attention. So and I would also like to reinforce using those disaster hotlines are really important. We've actually seen I think an 800% increase in some of those hotlines. So people are certainly calling. People unfortunately are very distressed. And this is a really important issue, I agree that we need to focus on. We collectively need to focus on.

>> Thank you very much.

In the interest of time, I'm going to move us along to invite our next discussant to share the virtual stage. Thank you so much, Hector. Really appreciate you.

Next up is Carolyn Chang.

>> CAROLYN CHANG: Thank you for including me in this very important discussion. I am an attorney. I have been practicing family law in Burlington County, New Jersey for the last 30 years. I am a past-president of the association of black women lawyers of New Jersey and I'm happy to be on this webinar this afternoon.

From my perspective the impact of COVID in my community I see two different lenses. The first lens is a personal one. And then the second lens is with regard to providing legal services to our community. Through my personal lens, my 27-year-old daughter tested positive for COVID-19 on April 19, 2020. She received her test results on April 4th. My daughter is young. She's only age 27. She's very healthy. She is a young person who goes to the gym every day. And she has absolutely no preexisting medical condition.

So for several weeks in late February

(Cell phone ringing.)

I'm sorry about that.

For several weeks in late February and early March, there was a rumor going around that black people could not contract the virus. This is clearly false. Even young, healthy, black people can and do contract the virus. My daughter was lucky. And blessed in that she only experienced mild symptoms. She lost her sense of taste, she lost her sense of smell. She had elevated temperatures, usually at night. And she had some chills. She was able to quarantine in her own room, and she utilized only one bathroom in the home until her symptoms ended and she left quarantine.

Now, I am mindful of the fact that many people do not have the ability to quarantine in that manner. She is now thankfully completely recovered.

The second personal lens that I want to spend some time on is in regard to my younger brother, who is only age 49, who became ill in mid March. He was experiencing signs of the flu and he tested positive for the virus. However, he did not receive his test results until he was in respiratory distress. He was directed to the ER, at a hospital in Somerset County, New Jersey. And he remained in the emergency room from March 24th through March 26th when a bed became available for him in the hospital. He was transferred to the ICU, and by Sunday afternoon, March 29th, he was intubated and placed on a ventilator. My brother remained on that ventilator for a month, and he is still today receiving some support at night

from the ventilator.

There were times within the last month where it appeared that my brother would not survive, because there were three separate attempts to remove him from that ventilator, and all three attempts failed. He was not able to breathe on his own. His airways had become so swollen that removing the ventilator tube from his throat just did not do much to help him breathe on his own.

The medical staff administered steroids to bring down the swelling in his airways and that was not successful. They attempted to lower the sedation and as he began to awaken, he began to experience delirium. He attempted to get out of the hospital bed, he pulled out his IVs, he pulled out the ventilator tube from his throat and at least once bit through the balloon which was attached to the ventilator tube in his throat. Finally the medical staff advised that the only option left for my brother in order for him to have a shot at removal from the ventilator was to do a tracheostomy on a 49-year-old man. Place it directly into his trachea by cutting a small hole into his neck. The ventilator tube would be attached by using what is referred to as a trach collar. This was performed only last Sunday and thankfully he has improved medically each day since then.

I've learned so much in the past month, such as the negative effects of being on a ventilator, especially for long periods of time. The patient must be heavily sedated in order to have a tube inserted into the throat which is extremely uncomfortable. When the patient begins to be weaned off sedation, they will probably experience delirium episodes. They may believe the medical staff are enemies and there are to hurt them. They may believe there are things, ghosts on their hospital beds, they may strike out against the medical staff who are providing care to them.

Until the sedation is completely out of the person's system, the brain may not function properly and their short-term memory may be limited.

So with my personal experiences, you may ask why are these two personal experiences so very different? Well, my daughter is young and healthy with no preexisting medical conditions. My brother is young, fairly healthy, but extremely asthmatic. I was very glad to see one of your speakers, I believe it was Miss Peacock include a slide on COVID-19 and asthma. These two very different outcomes gave me an opportunity to think about the other lens through which I view the impact of COVID-19 on our community. And that's the legal lens.

So my daughter who's young and healthy is newly employed with a start-up company, which provided her with no medical coverage. She had aged out of her father's employer-provided medical insurance. Had she become extremely ill, and had to be hospitalized, that would have surely placed my husband and I into a very scary financial predicament. My brother is employed with a particular department within the State of New Jersey for a few years, and he has good medical coverage. However, he had not prepared for this unexpected, severe illness and long hospitalization where he was literally in a coma for several weeks. He had not prepared, had not signed a power of attorney, or an advance healthcare directive, otherwise known as a living will.

With a parent or an adult or a child or an adult with a developmental or intellectual disability, we should think about whether a guardianship application should be filed and obtain a judgment of guardianship for that individual in order to be able to make certain legal decisions and medical decisions for that individual.

My brother, fortunately, was perceptive enough to give verbal instructions from the medical staff when he was moved from the regular hospital floor to the ICU and he made a decision when he was able to to allow my sisters and I to make medical decisions for him while he was hospitalized. However, that verbal instruction that he provided to the hospital staff does not work with getting information from my brother's employer as to whether he is continuing

to be paid while he's hospitalized. You need a signed and notarized power of attorney for that. That verbal authorization which he provided to the hospital does not work when talking with his creditors about giving extensions on his monthly mortgages, his utilities and service agreements. You need a written and notarized power of attorney for that. That verbal authorization does not work when talking about my brother's business ventures, you need a signed and notarized power of attorney for that.

So the lessons I've learned here, it's very important. And it's to get a power of attorney drafted and executed. Get an advanced healthcare declaration or living will drafted and executed. Or file a guardianship application for an adult with disabilities and obtain a judgment for guardianship.

The final lesson I learned in the way COVID-19 impacts our community is knowing how to interact with the medical staff who may be providing care for your loved ones. Your loved ones may be hospitalized or worse in an ICU or maybe on a ventilator. So some of the suggestions I have is to choose a family member who is assertive and who can effectively advocate for your loved one who is alone and afraid in the ICU. Be assertive, but do not alienate the medical staff. Keep in mind that these doctors and nurses are providing day-to-day care for your loved one.

Know that most if not all ICUs have iPads and can and should provide Face Time calls to family members with the patients. Facetime with your family members who is on a ventilator is really necessary. He or she may not be able to respond to you. But they can hear your voice. Hear the sound of your voice will provide comfort and provide assurances that they're not alone.

Lastly, appreciate the fact that the medical staff can tell you the daily updates and provide good care for your loved one.

We should also be aware that the State of New Jersey just issued a directive from the health department a few days ago which says coronavirus patients with developmental or intellectual disabilities must be allowed a support person at their side during hospital stays. The health department noted that limitations hospitals place on visitors to slow the spread of the coronavirus should take into account that patient care and well-being and that having a support person is essential to patients' care, especially for patients with disabilities, where the disabilities may be due to altered medical status, intellectual, or cognitive disability, communication barriers or behavioral concerns. We all know that hospitals have developed guidelines in response to the coronavirus that in many cases bar visitors with some exceptions for pediatrics and maternity patients. The latest directive from the health department in the State of New Jersey ensure that patients with developmental and intellectual disabilities can have a family member, personal care provider, or a service provider at their bedside.

However, the visitor must be symptom-free, and must be regularly screened by the hospital staff with temperature checks according to the directive. The individual will be expected to wear personal protective equipment and will not be allowed to leave and return to the hospital. This visitor or advocate will have extremely limited access to other parts of the hospital.

A second support person may be permitted if the hospital has enough personal protective equipment, and determines that other individual is necessary.

The directive says the hospital will not be permitted to bar the visitor or the advocate from the patient if the hospital is not experiencing a shortage of protective equipment.

So my question, like Hector's, would go to the issue of the psychological issues that we will face with our family members at the end of this pandemic. I think that is going to be the future wave, in terms of what to expect from COVID-19. I think we will have an enormous amount of people who will be coming home from the hospital, recovering not only from



medical issues, but also from severe psychological issues.

And I believe that is something we need to prepare for in the future. Thank you.

>> Thank you so much, Carolyn. Sorry, the audio was cutting out.

Next we wanted to wrap up, and I'm going to pass the virtual stage over to Ilka Riddle to wrap us up. So Ilka?

>> Can you hear me now? I was already talking for quite a while but I guess nobody could hear me.

So again, thank you Carolyn for sharing and unfortunately we are really out of time. I saw that there was a lot of information shared in the chat box, and that information will be available in the archived webinar.

So also I wanted to make sure that you know about the public health is for everyone toolkit which we hope you can contribute to. You see it on the last slide here. Because we want to collect COVID-19-specific information and resources and tools for the public and for people with disabilities. And then finally, we wanted to make you aware that we're going to hold a disability in public health COVID-19 town hall on June 2nd at 3:00 p.m. eastern time. We invite you all to join us and more information on this will be forthcoming. Thank you so much to our speakers and for everybody to attended and stuck with you and posted great questions. I think for people who need a certificate of attendance Adriane, can you put in the chat box where they have to send their information or email to so they can get a certificate? And with that, I want to close out our 4-part webinar series. Thank you all. Have a great morning, afternoon or evening, depending on your time zone from which you are calling in. Thanks again.

>> Thank you.