

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES (AUCD)
NETWORK PUBLIC HEALTH WEBINAR SERIES ON COVID-19 – SESSION 1:ADVICE FROM MEDICAL
PROVIDERS

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Remote CART Captioning

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This transcript is being provided in rough-draft format.



>> Hello, everyone. Sorry for the technical difficulties we have had. We hope it's gonna go a little bit smoother now. Well, welcome to the AUCD network webinar series on people with disabilities and COVID-19. Today is the first of four webinars. Today we will provide advice from medical providers. I'm Ilka Riddle, an associate professor at the University of Cincinnati and Cincinnati Children's Hospital. I'm also the director of the University for Cincinnati Centers for excellence and developmental disabilities. And chair of the AUCD's health and special interest group.

With Dr. Adriane Griffen, I'm one of the facilitators of this webinar. First, we would like to thank all of you for joining us today. We know how busy everyone is with working from home, school at home, and taking care of loved ones in these very challenges times.

Before we begin with the actual presentations, I would like to address a few logistical details. Because of the large number of participants, your audio lines will be muted throughout the webinar. However, you can submit your questions at any point during the presentations 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.

We will compile your questions throughout the webinar and address them at the end of our

discussions. And our question and answer marshal. Please note that we may not be able to address every question 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 a survey at the close of the webinar. We ask you to provide feedback on the webinar and provide suggestions for future topics.

So, why are we doing this webinar series? Over the last few weeks, we have learned quickly that the needs of people with disabilities and their families during the coronavirus pandemic are not well-addressed. And we decided that information from experts in our field of developmental disabilities could be useful to awful us. Therefore, we created this webinar series with the hope that you will find it useful. Now I would like to welcome today's distinguished panel of speakers and thank them very much for agreeing to present today.

All of them are heavily involved in responses to the COVID-19 pandemic and we feel fortunate that they are with us today. Our panelists today include Dr. Georgina Peacock from the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. Dr. Larry Yin, pediatrician and director of -- and at Children's Hospital Los Angeles. The founder of the Lee specialty clinic in Louisville, Kentucky. A member of the executive board of the American academy of medicine and dentistry. And finally, Dr. Laura Stough from the Center on disability and development at Texas A&M University.

In addition to our fantastic speakers, we have also invited two great discussants and our marshal. Hector Ramirez and Lesley Cottrell. From the West Virginia center for excellence in disabilities. And Dr. Steve Sulkes pediatrician and director at the Strong Center for developmental disabilities at the University of Rochester. And President of the executive board of the American academy of developmental medicine and dentistry.

Our panelists will speak first. Followed by remarks and thoughts from our discussants. Our A and marshal will then lead us through questions. If

Adriane is on, I will now pass the mic to Dr. Adriane Griffen who will get us started with a few words about public help.

>> Adriane Griffen: Thank you, Ilka. I believe my audio is back on. Thank you, everybody. I'm sorry for the technical issues. Well, thank you all very much. I just want to echo the welcome that Dr. Riddle shared with you. In preparation for today's series, we were asked to think through -- how can we slow this information down a bit so that it is in more bite-size nuggets? It feels like, you know, you're trying to drink a small cup of water from a fire hose.

So, this four-part series is our attempt to really give you the key pieces of information that you need when you need it. First off, we were asked if we could please define, what is public health? So, this is our short introduction for this webinar and the webinar series.

Defining public health is easier said than done. It is something that is defined differently by different people. So, we are presenting for you a couple different ways that it is defined. Just to give you context and for this to serve as a framework for our remarks today and throughout the webinar series.

Our first definition is from the American Public Health Association. And they define public health as being present to help promote and protect the health of people and the communities where they live, work, learn and play. So, really, you can think of public health as being everywhere that you are to help prevent you from getting sick or prevent you from getting injured. Also, public health promotes wellness by encouraging healthy behavior.

The other definition that I like is actually an oldy, but a goody from Winslow back in the early 1920s is around seeing public health as both a practice of science as well as art to promote health and prolong your life and takes place through a community effort that's organized.

But the definition that's the framework for the AUCD and our National Center on disability and public health actually comes from research that I have done with the AUCD network. And we propose that public health is for everyone. And that this includes people with disabilities. Public health shares tools for managing change, for thinking creatively, and for

doing things differently. Which is the current situation that we find ourselves in.

So, just let's take a moment at the beginning to define how we are thinking about public health for today and for this series of webinars. We hope that you find that helpful. And without further ado, I'm going to pass the virtual stage over to Dr. Georgina Peacock who is working tirelessly now at the emergency response center at CDC. So, I'll let you take the microphone, Dr. Peacock, thank you.

>> Dr. Peacock: Thank you. I'm Georgina Peacock, a developmental pediatrician. And in the CDC response to COVID-19, I am co-leading the community and at-risk populations task force. And I'll talk about that a little bit in a few slides to just describe the work that we're doing.

In typical times I'm the director for the division of human development and disability. I wanted to start out by acknowledging that these are very anxious times. It's very extraordinarily stressful. Especially for people who maybe at higher risk for severe illness.

And I do hope that today's call will help just a little but answering some of the questions you may have and in helping you make a plan. So, I'm gonna sort of back up to the beginning and talk a little bit about coronavirus. This is a large family of viruses that cause respiratory illness. And coronaviruses as a whole were first isolated in the 1960s. And they're named coronavirus because of the crown-like spikes on their surface.

They can spread among animals and people. And, we call this zoonotic. So, COVID-19, the virus that is currently causing this pandemic, was first, as you likely know, identified about 5 months ago. And because it's a new virus, we still have a lot to learn about it. Its named by the World Health Organization in the following way. The co stands for corona. The VI stands for virus. And the D stands for -- and 19. So, that's why we're calling it COVID-19 because it was first seen in 2019.

As you all know, it seems to spread easily. And it is sustained in many communities in the United States. And what this community spread means is that many people have been infected in -- in a particular area. And we're not always sure exactly

how someone is becoming infected because there is a lot of spread in communities.

The virus is thought to spread mainly from person-to-person. Between people who are in close contact with one another. So, within about 6 feet. It's spread through respiratory droplets produced when an infected person coughs, sneezes or talks. And then that can land in the mouths or noses of people nearby.

And/or possibly be inhaled into their lungs. It may be possible that a person can get COVID-19 by touching a surface or object that has the virus on it and then touching their own mouth, nose and possibly eyes. Though it is not thought that this is the main way the virus spreads.

So, to talk about what we know about the virus today, we know that there are -- have been reported more than 600,000 people in the United States with coronavirus. And about 24,000 deaths. These are really strange and humbling times. And I certainly send my condolences first out to those people who have been personally affected by serious illness and death.

We are also seeing some positives. We're seeing it appears that we're seeing some slowing of cases. And this is due to the things that many people are doing across the country that look to be flattening the curve. And flattening the curve, as you know, is what we are trying to do so that we can spread the impact of the virus and the impact of that illness so that the health care and critical infrastructure that we need to keep society going is used over a period of time instead of being needed to be used all at once.

So, we are trying to slow that spread of disease. And the things that you all are doing such as physical distancing, staying at home as much as possible, and taking those individual measures that we'll talk about in a little bit like face coverings and washing hands and things like that are really making a difference.

So, talking a little bit more about that, you can see these different recommendations on preventing COVID-19. It's important to clean your hands often. Stay home as much as possible. To avoid touching your face, eyes, nose, and high-touch surfaces. To

cover your nose and mouth with a cloth face cover. And clean and disinfect. And I list a website here that you can go to.

And it's important to think about what to do if you do get sick. So, some people, for example, have direct support providers. So, thinking about what may need to happen either if you or your direct support provider gets sick. Friends and neighbors, local service agencies that can provide support if this does happen. Having enough household items including a 30-day supply of over-the-counter and prescription medicines. Some health plans we understand are allowing for the 90-day refill on prescription medications. And this is something to discuss with your health care provider.

And another thing that can be helpful is to make a photo copy of your prescriptions should you need those. Here is some information about what to do if you do get sick. So, the recommendation is to stay home and contact your health care provider if you are having some of the symptoms of COVID-19. These include things like fever, cough and shortness of breath. Though there are other symptoms that you can access on the CDC website.

So, if you have mild illness, you may be able to recover from home. And there are instructions, again, on the CDC website for what to do if -- how to care for yourself at home. And I refer you to those. However, that doesn't mean that you shouldn't seek attention if you need it. So, seeking medical attention is very important if you have certain emergency warning signs such as trouble breathing, persistent pain or pressure in the chest, new confusion or an inability to -- for someone to arouse you. And bluish lips or face.

So, now I'm gonna take a moment to -- before I talk about some of the specific information here about people with disabilities, you wanted to let you know what the work that we are doing on the community and at-risk populations task force. We're focused on reducing morbidity and mortality among populations although risk from getting serious illness from COVID-19. And we're also focused on reducing those secondary impacts and consequences of the pandemic. And finally, we're supporting efforts in communities to both reduce spread and also support

the reopening of communities in a thoughtful way.

And some of the teams that we have within our task force that are working on this in -- that are working on this include our team that's working on at-risk underlying medical conditions. And this team is focused on communication outreach and partnership to reduce the severe illness from COVID-19 among older adults who are over age 65 and those with high-risk medical conditions.

And we -- some of the medical conditions that we are concerned about are those people who have chronic lung disease or moderate to severe asthma. Those people who have serious heart conditions. People who are immunocompromised. And this may mean that someone is going through cancer treatment. They may smoke. Have bone marrow or organ transplantation. Immunodeficiencies. Poorly-controlled HIV or AIDS. Or prolonged use of corticosteroids or other immuno weakening medications. And one more thing about this, this doesn't mean that you have asthma you should stop using your inhaled steroids. Inhaled steroids are not the type of prolonged corticosteroid use that we're talking about.

And even these things that put you at a higher risk, you should not stop them unless your health care provider helps you make that decision. You should continue to treat -- take the medications to treat your underlying conditions. Other people that we believe to be at higher risk are those with severe obesity with a body mass index of greater than 40. People with diabetes. People with chronic kidney disease undergoing dialysis and people with liver disease.

Another group -- another team that we have within our task force is our team that is focused on what we're calling high-risk populations. And these populations are at risk for other reasons because of either social context, because of the functional access needs that they have and other things like that. So, these include minorities including race and ethnicity. Those -- some people that are living in rural areas. Some people that are experiencing homelessness. Some people with disabilities and people who maybe experience substance use issues.

And then the final team that we have working within our task force that I wanted to mention is our

social behavioral health team. And our social behavioral health team is really focused on thinking about what is needed for daily life and coping. Focusing on anxiety and stress. And also, creating a long-term plan to support the social behavioral wellness in communities across the United States. And in particular, thinking about ways we can reduce the secondary impacts of the pandemic in a public health way.

So, now I'm gonna turn back to my slides. And you'll see here that we don't believe that specifically having a disability puts you at higher risk for severe illness. However, some people with disabilities may be at higher risk for infection or severe illness because of underlying chronic medical conditions. Some may be at risk because of having limited mobility or limited ability to get to the care that is needed. There may be problems with understanding -- or understanding information that is provided or the information may not be provided in a level that is helpful.

There may be, also, concerns about not being able to communicate symptoms of illness. We do have some resources on the CDC website for people with disabilities. And we also have a number of American Sign Language videos that have been provided so that those can be communicated -- the information can be communicated in different ways.

mentioned direct support providers earlier. And I think it is important to think about a plan for if your direct support provider does become ill. Here are some things that you can recommend when working with your direct support provider. I think it's a good practice when either that provider or really anyone that's coming in and out of your house. The first thing that they do is wash their hands with soap and water. This is not a quick washing of hands but washing your hands for -- with soap and water for about 20 seconds.

This can reduce possibly that transmission if a person is ill and maybe asymptomatic and they've touched their face and then they're touching other surfaces. Cleaning frequently-touched surfaces and equipment. Wearing face -- cloth face coverings. And you can see that there are recommendations for routine cleaning and disinfection in households.

I also provided here a link on this slide. And I believe anyone -- these slides are going to be posted. And if not, we can make sure to get those to Adriane so she can send them out. But there is some guidance also for health care personnel caring for people with confirmed or possible COVID-19 that maybe helpful as well as information on the website about how to care for people not -- that don't require hospitalization.

So -- excuse me. To end my presentation, I think it's very important that we acknowledge how stressful these times are for many of us across the United States. And so, here are some, you know, brief reminders that maybe we can all take to heart to take breaks, to take care of yourself. To connect with others. And this may be connecting with others in ways that are different than you usually do. Make time to unwind. And we do have some more information on the stress and coping part of the website on the CDC website as well as we are doing a number of things where we are monitoring what's going on in the US by looking at what's being posted on social media, looking what's being posted in different places and then trying to produce communication that will go out on different social media channels to help remind people of supports that are out there should they need them.

I've provided to Colin -- sorry, hotlines on the website here. The disaster distress helpline and also the National domestic violence hotline. These are numbers that can be called, and they can be texted. And I think with that I would like to turn it back over to the moderator and thank you for your attention and thank you for all you're doing to help both reduce the spread and take care of your loved ones in this very challenging time. Thank you.

>> Thank you. Appreciate you, Dr. Peacock. Next up we're going to hear from Dr. Larry Yin who will share his pediatric perspective from his practice at the Children's Hospital Los Angeles. So, I'll pass the virtual microphone over to you, Dr. Yin.

>> Dr. Yin: I'm thankful for the opportunity to speak today. And wanted to echo Georgina's comments about, you know, trying to keep everybody safe in this current strange time that we're in. I'll get my own slides here. Okay. So, what I wanted to

share with everyone, and some of this is an overlap with what Georgina has been talking about is the ideas around staying safe and steps to prevent spread of infection. With some specific ideas that you might want to include in your home.

You know, obviously hand washing is very, very important. You know, we talked about at least 20 seconds of hand washing or how long it takes you it sing the ABC song. As really good ways to prevent spread of infection. As well as having hand sanitizer that has more than 60 to 70% of alcohol in it. And the other helpful item to have in your home is hand moisturizer. If you're washing your hands a lot, your hands will get dry and make sure they stay moist. Social distancing in the home as much as you can, another important factor.

And frequent cleaning of the high-touch areas like doorknobs, cell phones, controllers, light switches, et cetera, and any dial. I put on here as well not to share towels. Especially kitchen towels that we typically have in the home.

Usually what I tell parents is the kitchen towel where everyone goes to wash in the kitchen and uses the same towel is one way to spread infection. You can do the same, obviously, in the bathroom. Covering your sneezes and coughs with tissue. But more importantly, after doing that, throwing away the tissue. Often times we hold them in our hands, put them in the pockets, in our purses, et cetera. It's good to throw them away as soon as you sneeze or cough. In terms of medication and special formulas, as Georgina was saying previously, having enough of a supply. One month would be ideal. But at least two weeks of having your medications at home as well as the special formulas if your child might be on.

For masks or cloth coverings in the home. Children who are over 2 who are sick, you might want to consider having them wear a mask at home and isolate younger kids, if you can, as best you can. And then practice the hand hygiene with them as well. When you're in the community, if you have -- if you have to be out in the community, and if you're in your car, remember to try to have disinfectant wipes in your car if you go out. That way you have an ability to wipe your hands, clean your hands or clean around the steering wheel so that you don't prevent spread of

infection that way.

And obviously, when you're out in public, social distancing and wearing masks are also gonna be important. The issue of doctor visits. Right now, we're recommending that doctor visits occur only if necessary. And necessary would include making sure immunizations are kept up as well. And some of the offices in our community have -- have used telehealth and telephone care to check in on their patients. So that there's, you know, reminders. Or if you have concerns about infection or spread of infection, you can reach out to your doctor's office that way.

If you do need to go to your doctor's office for a visit, make sure to call ahead so they can prepare their office for you if your child is sick. Or they may opt to use telehealth and speak to you via the computer or phone.

And piggybacking on Dr. Peacock's comments around what to do when you get ill if your child gets ill. You know, the typical signs are fever, dry cough as well as stomach pain or diarrhea. And so, it may look similar to many other infections your child may have had. With this infection, you want to isolate your child from others if you can. It's your home. We understand that sometimes that's impossible. But at very least, if they're sick and they're coughing, have them wear a mask. And usually with this infection, it typically gets better by a week or so.

The things that we talk to our patients about is when to call us. And so, if the fever is lasting for more than four days or it's not improving with medicine, like Tylenol, we definitely want to know about that. We definitely want to know if your child's having a hard time breathing or is breathing faster. Those -- those are issues that we definitely want to know about right away. If your child is not drinking or eating or not going to the bathroom as frequently, we want to know about that as well. And if your child's not as active as typical. Or they're having a harder time waking up from a nap or you're simply worried. We definitely want you to reach out to your doctor to talk about next steps in planning for care.

In terms of trying to continue to receive community support safely, we resorted to using a lot of technology. Both high-tech and low tech. From

the low tech standpoint, we've resorted to using email correspondence with our families where we will provide helpful tips and activities. We also are reaching out to our patients with phone calls just to check in to see how they're doing. And then on the higher tech side, we have been using telehealth therapy.

So, our therapists, speech and language pathologists, occupational therapists, mental health professionals as well as ADA therapists are in our community now providing a lot of telehealth support and to continue the ongoing therapy sessions that they've already had with their providers. Or their families.

Again, we're offering video chats with our providers as well. And you wanted to remind everyone during this time, special education services should still be continuing. And working with your local school districts about how they are managing to provide special education services during this time is gonna be important so that there's no break in the delivery of those services.

Obviously, the UCEDDs across the country are resources to all of you in regards to the types of activities we're doing around this current time period. But even more importantly, even after this time period. We're still available to you. I wanted to remind folks that the State Departments of developmental disabilities and their offices are also a great resource for local communities to understand where folks can go for extra help. And then the State Department of Education is also available for everyone's support. For those who have individualized education plans.

I think the -- in our community, providers are still coming and making home visits in early intervention. And we've given recommendations around that that are similar to Dr. Peacock's in terms of ensuring that they're not ill before they come. And then when they do come, making sure they wash their hands. And for extra layer of safety, if they would wear a cloth mask when they're delivering care within your home.

And then in terms of wellness tips, I wanted to talk about and reiterate the stress that everyone is feeling around this time. But it's also, including

children. And what we're seeing right now is many children with symptoms of anxiety, symptoms of depression and symptoms of basically loneliness. Because when you're in self-isolation, you know, at home, you're not going to school. And kids miss their friends. And they feel kind of alone out there. And so, the things that you want to watch for in your kids is excessive fear or worry. Maybe changes in their sleep or eating habits. More difficulty with their concentration. Or just simply excessive crying.

And understand that each child in your family is gonna react differently. And you as parents know your children best to understand, you know, the differences in behavior that should be addressed. I think that, you know, taking time to share with one another about their feelings and validate those feelings is gonna be another important step in trying to decrease some of the angst or anxiety that some kids are feeling. And understand that children just really want to feel safe and protected. And parents can empower their kids by taking action. By having them help in disinfecting their house. Reaching out to classmates and grandparents via tele to check in with them to see how they're doing during this time period is another great way to help empower kids and make them feel like they are also contributing to preventing spread and getting over these infections.

I wanted to make sure that parents really start to pay extra attention to what their kids are watching on YouTube, TV and social media and be able to explain, you know, what they're watching as well. And that could be a good time period to -- a good time, at least, to connect. And then we always -- we always tell parents to be truthful -- truthful with the information. And more importantly, provide it in a developmental level that's appropriate for your child.

And to remind everyone that we want to avoid using words that might blame others for this infection. And then finally, as part of wellness, you know, we really want folks to ensure that they take time for themselves. Take a break from the news. And I think that that's something that many of us are on news overload. And it really is important to turn off your iPad, turn off your computer, turn off your phone for a while each day just to relax. And ensure your kids do the same.

During this time, you know, staying connected with family, with friends, with teachers and faith-based leaders is another important strategy to improve personal wellness. And for your kids who are at home from school, it's creating and sticking to a daily schedule. That's what your kids are used to. And trying to implement that in your home will have great benefit. And what I'm hearing already from some of my patients is, the kids are actually doing better at home because they're able -- the parents are able to enforce a schedule. And they're able to stick to it. And their kids are doing better with their homework, kids are doing better with their activities, et cetera.

And lastly, during this time, building in daily exercise for everyone. Either in the home or in your backyard or in a safer space. And I think on my last slide I have a lot of different resources that are available that I think are great including some free and low cost Internet services. The USDA website has a free resource for finding meals near where you live. You simply put in your address and there will be a map of areas that are providing free meals. I think the CDC symptom checker is a great tool.

Just if you have questions about your own -- if you're developing an illness, to go there and take a look and put in your symptoms and see what it says. I've also added some tips about how to talk to kids about coronavirus as well. And I've included some video. And lastly, you know, understanding the number of folks who have passed from this infection. I've added two resources.

A resource about helping students who are grieving through this pandemic. I think that that's another important population that we need to be thinking about in this time given the number of folks who have passed from this infection. With that, I think that's my last slide, Adriane, I'll give it back to you.

>> Adriane Griffen: Thank you. I appreciate that. And just for folk toes know, we will be sharing these slides. They are available right now in the download materials section. The resources and links are yours to use. Thank you, Dr. Yin. Next, we will hear from Dr. Matt Holder who is going to share more across the life span, adult perspective, dealing with COVID-19. I'll turn it over you, Dr. Holder.

>> Dr. Holder: Thank you, Adriane. Thank you for spending your afternoon with us and thank you to the interpreters for paying such close attention, thank you. I'm going to talk to you about a couple of things. My background here is I have been in the field of intellectual development disabilities medicine for almost two decades now. I'm one of the founders of the American Academy of Developmental Medicine and dentistry and the chair of the medical advisory committee for Special Olympics and run the Lee specialty clinic in Louisville, Kentucky, which I will talk about later.

Right now, I'm going to start off with what I would consider to be a worst case situation. And many of you in the advocacy circles have heard about this. But I know a number of folks who have not heard about this issue or have not heard about the concern about this issue. Of and really what it is is let's say that you have an intellectual or developmental disability and you find that you're in the worst case scenario. You are now in the hospital. You are short of breath and now you are going to the ICU and there's a question about whether you should have a ventilator to support your breathing or not.

And without it, likely you will die. There is a worst case scenario that has been talked about out there whereby there are more people who need ventilators than there are ventilators. And at that point the doctors are in a very difficult situation. They go into a triage mentality. Much like what would happen in a war or some kind of disaster like that.

And their job is to assess who should get the ventilator based on a number of factors and who should not. There are guidelines, published guidelines that exist, that were in place in some states and have been floating around that would suggest that people who have -- depend on the term -- but I've seen congenital syndromes, intellectual disability, the old term for that. And basically, suggesting that would be a reason to deny somebody the use of a ventilator. Obviously, the disability community was very upset about this and there's been a lot of progress made in this area just very rapidly in the last two weeks.

And what we've seen, I put a quote up here from the Office of civil rights and HHS in Washington,

D.C. And basically, the point is to say that it is really a discrimination issue. It's a civil rights issue. And so, the guidance that's been put out has pointed to this and said, well, you cannot discriminate against somebody on the basis that they have a disability.

This mainly has come from lawyers and, you know, policy writers. And when I've talked with them, they all express a little bit of fear in telling doctors how to practice. And I understand that. But there is -- I think that this has gone a long way. But I think that from my perspective over the last 20 years I've observed that most of our doctors do not receive enough training about intellectual and developmental disabilities. And what I'm concerned about is that person with intellectual disability who needs a ventilator, maybe they are not discriminated. They are put up for consideration for a ventilator. That technically, they are now not being discriminated against. However, there is certainly lots of literature out there that suggests that people with intellectual disabilities have shorter life spans.

And one of the ways that physicians may decide who gets a ventilator and who does not is based on how many more years of life they're expected to live. And our point, and this -- we've put a statement on the American academy of developmental medicine and dentistry's web page basically saying that the average physician does not understand the population of people with intellectual and developmental disabilities enough to use the literature out there to understand the life span. It's not just that for us, but we have to go a step further in the advocacy and state that the medical community doesn't understand people with I/DD enough to make decisions about their disabilities. What they should look at are more universal indicators for who would get a ventilator and who wouldn't.

Also, there's a quote here from the Kentucky protection advocacy group. They sent a letter to our governor basically asking the same kind of thing and saying, you know, we, you know, we respectfully request that we not discriminate. But furthermore, that when these kinds of decisions are being made that they're really considering the person's likelihood of surviving this particular issue. The fact that they have COVID-19 and not looking 20 or 30 years down

the road.

So, I just put that up there. And I have links at the end. So, for anybody who is interested in advocating around this issue. Another issue that has come up, and I've seen it locally here and I've heard about it around the country is the issue of accompaniment. If you have an intellectual disability and two to the hospital, it's likely that the hospital has a policy that says you should not have a visitor. Period. With you.

And this makes sense for a large portion of the population. However, we have patients, many of us have patients, who have communication difficulties. They have needs that the guardian or their support provider can -- can provide. And there really is risk to the patient of not having that person with them.

And not only that, but in some scenarios, if you have -- we have patients who are prone to behaviors. And so, if they're -- if they're guardian or their support person is really their mouthpiece and they're -- they're the ones who interpret their environment for them, they can be a source of soothing and calm.

And so, hospitals, unfortunately, don't necessarily understand that by not allowing this person to go back with the patient that they're taking the public health stance. Which is understandable that they want to try to prevent spread. But in these particular cases, if somebody starts to have a significant behavior, it's quite possible that there are a whole lot of other people that are gonna get involved with that. And more people will potentially be exposed in that situation than having the one support person. So, our recommendation in this scenario is that -- and certainly in some cases -- people be allowed to have their support person with them. And, of course, there needs to be sort of a risk-benefit analysis that's done with that. Not every person needs to have a support person back with them. But certainly, this can be an issue.

And real -- really, I kind of look at this as an ADA issue. The operable term is reasonable accommodation. Which is typically what is used in the ADA for somebody who is hearing impaired, for example, to have a sign language interpreter. It's the same kind of concept here. And this is just an issue that is very near and dear to us.

Now, what I'm gonna talk about for the remainder of my portion of the talk here is what we've done at the Lee Specialty Clinic. Just to describe the clinic in Louisville. We focus primarily on adults. But older children as well. With intellectual and developmental disabilities. And that's our -- entirely our patient base. We are an interdisciplinary teaching clinic. We provide a number of different specialties, medical, psychiatric, dental, physical and occupational therapy, speech. And a number of other specialties that I've listed here and some more on top of that.

We are funded by the Centers for Medicaid and Medicare Services and the Kentucky Cabinet for health and family services. Specifically, the behavioral health and intellectual and developmental disabilities. And what I want to talk about is since this pandemic has occurred, we have tried to shift what we're offering and what we're doing with our patients, like many health care providers have, to being completely online or as online as possible.

And what we have also done is try to shift our focus a little bit. So, we're focusing, of course, on the routine care that we provide. But we're also operating under one very important assumption. And that is that the emergency room is probably the highest risk that anybody can go in terms of being exposed to the COVID-19 virus. If I to roll the dice, that's probably the last place that I would want to go. So, what we want to do in addition to all the wonderful things that we talk about now in terms of preventing the virus, we want to try to prevent people with intellectual and developmental disabilities from needing to go to the emergency room or the urgent care or the health care setting in general.

And so, the best way to do that is to be as preventative as possible. And why do we want to do that? Some of you may have seen The New York Times article that came out I think just last week that mentioned that there was a study done that talked about -- that people with intellectual disabilities in the group home setting, they calculated were contracting the virus five times -- at a rate five times greater than the general population. And they were dying at a rate five times greater than the population.

And that has I'm sure to do with the living

environment and a combination of that and pre-existing medical conditions. Not the fact that they have a disability. But the point is, there is a higher risk. So, we want to try to focus on prevention. And the first thing that we want to do, which as Dr. Yin mentioned earlier, is really focus on mental health. These are very stressful times. And for our patients, what we've noticed is the disruption in routine seems to be creating some issues.

And so, what we want to try to do very quickly. And now that we have a quarantine and everybody is trying to stay home as much as possible is to establish a new norm, a new routine. And try to stick with that as much as possible. That seems to be a fairly successful method for our folks. I will mention that Special Olympics has a program, Strong Minds. I have a reference for it later. That talks about anxiety-relieving techniques and things like that for specifically for people with intellectual disabilities. Of course, even everybody now is using technology. Video technology as a replacement for social interaction at this point.

And as Dr. Yin mentioned earlier, staying away from the news. That stresses people out. If you have it on CNN all the time or whatever your news channel is, there's a lot to be concerned about. It's good to stay away from those sorts of things. And also keeping the late night screen time to a minimum. This is going to disrupt your sleep cycle. And I will talk about that in a second.

Going along with that, activity, physical activity if possible is one of the best antidepressants that exist. If you can get outside just for a little while, it's wonderful. If you can do some physical activity, even if your house, you're going to burn off some calories, start to feel better. Really, it's hard to do. It's hard to get in that routine when you're in your house. But please, try to increase your physical activity.

And Special Olympics has some offerings for this as well. There's the School of Strength videos which they developed in partnership with the WWE. They're very fun. And there are some Fit Five videos which is what they're called, other fitness-type videos. You would encourage everybody to try to be a little more active.

Personal hygiene. You know, everybody's

routine is off. Everybody is at home. I would bet that there are hundreds of people listening right now who are probably still in their pajamas. And, you know, I think it's important that everybody take your -- take your shower the same day that you normally would. And part of the reason for this is because, like I mentioned, sleep is very, very important. And the further back you push things, just because you're at home, the later you're gonna stay awake, the harder it is to go to sleep. And unfortunately for our patients, when sleep starts to go down, depression starts to go up. Mental health concerns start to go up when sleep hygiene gets a little bit bad.

Obviously, hand washing is very important. We've talked about that. Our OTs, our trying to help via videos to, you know, talk about our hand washing with our patients and just kind of go over that and practice, practice, practice. Oral hygiene. Very, very important. A lot of people don't understand the relationship between dental pain and behavior.

And one of the best ways to prevent dental pain in the first place is to have good oral hygiene. So, we want to make sure everybody's brushing their teeth as much as they can. And our dentists have made these recommendations. This is coming from our clinic, there's no scientific studies on this. But just intuitively for the caregivers who are brushing somebody else's teeth, brushing someone with intellectual disability's teeth, they're recommending no power brush. Because the power brush tends to spray droplets around. So, if this person happens to be an asymptomatic carrier, now you have droplets that are virus-infected spread all over the place. So, a manual toothbrush is a better scenario.

Typically, your dental hygienist recommends to brush the tongue as well. But they're saying don't do that right now because you can trigger a cough reflex. And we don't want to do that because we're going to spread the virus. Nutrition a big issue. Hard to get to the grocery store, delivery services aren't working well and they're out of a lot of things and people are hoarding.

People are going out and buying the kinds of foods that have a shelf life of years. And so, they're kind of neglecting their fresh fruits and vegetables.

And, again, those kinds of foods are what you feel good. If you're carb overloading day after day after day, that's gonna eat away at you. And we want to try to avoid that. Hydration. Very, very important.

One of the biggest issues that sends people to the emergency room and causes behaviors in people with intellectual disabilities is constipation. Hydration is one of the best ways to prevent constipation from happening in the first place. It also prevents a whole lot of other things. Caffeine, again. With that change in routine, there might be a -- a propensity for somebody to drink more coffee, cokes or teas or whatever. That's going to mess with your sleep cycle. But also, it can trigger behaviors, again, if somebody is getting more caffeine than they're used to.

Another important thing, vitamin D and sunlight. Try to get 15 minutes of sunlight a day if you can. And you want those vitamin D levels up there. Decent evidence shows that vitamin D is pretty good for the immune system. Certainly, a lot of people, and especially people with intellectual and developmental disabilities tend to be vitamin D deficient. Get as much as of that as possible.

And one last slide here. Just a couple of other it ups. Dr. Peacock mentioned having longer prescriptions. I would second that. That prevents you from going to the pharmacy or the doctor. Take your medications to prevent issues. Another interesting thing that came up is the now constant use of PPE in situations that people aren't used to seeing them in. And for people with intellectual and developmental disabilities, this may be concerning and even scary.

What we're talking about now is trying to introduce people to personal protective equipment and getting used to seeing people in masks and that kind of thing so that if they have to be to a health care setting, they're not as scared about it because they see people in much more P PE than they're used to. Another thing, track fluid in, fluid out and bowel movements. Again, constipation is just one of those things.

Also, if you have a need that arises, I would definitely request that you talk to your doctor for a tele consultation of some kind

Almost all doctors will do that right now. And if you have -- another service that I think is interesting, you know, I heard about this last year, is a service called Station MD. Which is a tele emergency service and they really focus on persons with I/DD. And again, there are group homes out there where the trigger for sending somebody to the emergency room is very, very light. And something, you know, a tele consultation from your doctor, from a tele emergency service like that can prevent somebody from going to the ER. For me, that's what it's all about right now.

And finally, I think the last thing is that we're talking about people with I/DD, but their care givers, they need to care of themselves as well. The burden of all that's going on right now falls to the care giver as well as the change in routine and caring for the person with I/DD and they don't get the break of going to the day program or going to the office like they used to.

So, it's very important for our care givers to follow all of this advice and to take care of themselves. And with that, these are some of the links to -- that I mentioned before. And I will turn it back over to Adriane. Thank you so much.

>> Adriane Griffen: Thanks, Matt. Appreciate your sharing. And, again, these links will be available in the slides. Next up, we want to welcome Dr. Laura Stough to the virtual stage here. I'll advance your slides and you can take it away, Dr. Stough.

>> Laura Stough: Good afternoon, everybody. This is Dr. Laura Stough and I lead here at the Center on disability and development at Texas A&M. I'm associate professor of educational psychology, faculty fellow at the hazards risk reduction center also here at A and M. And chair of the emergency preparedness SIG for AUCD.

As you heard from our previous speakers, the CDC has identified groups of people who are at higher risk for COVID-19. I would like to come back to the issue of risk factors for COVID-19. First of all, people with disabilities are most of them are healthy and should not be considered ill. However, there are some disabilities that include underlying risk factors that also intersect with the risk factors to COVID-19.

For example, congenital heart defects are quite common in people with Down's syndrome. Cystic fibrosis causes persistent lung infections. Prader-Willi syndrome can lead to obesity or type 2 diabetes. We need to be particularly alert.

Disabilities also increases with age. For example, the World Health Organization approximates that 20% of people age 70 or older and 50% of people age 85 or older report difficulty with activities of daily living. Related to this factor, people who live in nursing homes or long care or other congregant facilities, what we've seen certainly at the life care center in Kirkland, Washington, where the first confirmed death due to the virus was in February and where 37 elderly residents have died to date.

In Texas, we have the dubious distinction of having the largest population of any state of people with disabilities living in large institutions. We have over 4500 people with disabilities living in these centers. And we are seeing outbreaks of residents testing positive to COVID-19.

Additionally, Texas is home to over 3,000 nursing faculties and assisted living centers. Again, congregant facilities are ripe for outbreak. You know, shared public spaces, dining facilities and other spaces in which residents socialize. We see similar concerns about other such congregant living spaces. College dormitories, prisons and, of course, others. I'm going to pause and address my use of the word disaster with respect this to pandemic.

We disaster researchers talk about hazards. And in the current scenario, the virus is a natural hazard. It happens to take the form of a small collection of DNA that's enclosed in an envelope of fats and proteins rather than the hazards we typically think of such as tornadoes or hurricanes or floods.

The formal definition of a disaster is a hazard that seriously disrupts the functioning of a society and causes widespread human, material, economic or environmental losses. And I think that we can agree that the word "Disaster" does apply to the current situation.

Research, some of which we have done here at Texas A&M, has revealed potential barriers to services and supports for people with disabilities experiencing disasters and other emergencies even

when people with disabilities do not have underlying health conditions. For example, emergency communications such as for COVID-19 must be in accessible format. Broadcasts need to include sign language interpretation and notices about quarantines should be offered in plain language.

With respect to the transportation with cessation of bus routes and limitation in paratransit services, we need to ensure that people with disabilities can get to testing sites and doctor visits. For those with pre-existing health needs, we need it make sure that we have continuity of health services so that their conditions do not deteriorate.

Personal care commitments also offer health care. And with isolation procedures and more people contracting the virus, we need to make sure that these supports continue. Statistics reveal that people with disabilities are less likely to be employed, more likely to live in poverty. To think about how job losses and closings are financially affecting people with disabilities and their families right now. We see this in other disasters as a trend. Connected to this issue is housing. We need to ensure that people with disabilities can stay in the accessible homes they own or are renting throughout this crisis.

Finally, our research has revealed the difficulty people with disabilities have in reconnecting with supports and services once an emergency has passed. And at some point, our activities are going to transition back something approaching normal. So, how are we going ensure that people with disabilities will be reconnected to their service providers, medical appointments, supportive employment and social network?

I want to point out that some people with disabilities as have been suggested earlier will encounter barriers even inability to follow some of the current CDC guidelines for self-protection. Here are some examples of barriers that may occur. For example, some individuals with intellectual disabilities may have difficulties with understanding recommendations or implementing self-hygiene procedures.

Think about the direction to wash your hands for 20 seconds or stay 6 feet away from people. If you are not able to count or measure well, how are

you going to put these practices in place? You're going to need assistance, perhaps, to follow these practices. Challenges for people with behavioral disabilities. And they include personal intolerance to wearing a face mask or in avoiding close contact with others. People with some types of mental health disorders may be difficult to convince of the critical nature of the CDC guidelines or even actively challenge them.

Finally, guidelines that recommend covering coughs or sneezes or cleaning and disinfecting surfaces for some people with physical disabilities, these movements or procedures will require, again, assistance. In sum, I see these as challenges and perhaps barriers that some members of the disability community may encounter in following the CDC guidelines for self-protection.

What you see on this slide is a product that our center just produced to address some of these challenges. Here we've taken the CDC guidelines for self-protection, which are displayed across the top of the chart, and then cross-walked them with five broad disability functional types down along the left side. Then within each box of this chart, we list modifications and accommodations that might be used to support implementation of the CDC's self-protection actions.

For example, for individuals with cognitive disabilities, in the box in the top left-hand side, we suggest that perhaps using a timer or an assistive device to time hand washing might be an appropriate accommodation. For some people with physical disabilities, adaptations to the home environment might be a modification that makes frequent hand washing more accessible.

So, in sum, identifying and suggesting accommodation and modifications that might be made so that the CDC self-protection guidelines can be followed. A copy of this tool is on our center REDD -- Project REDD website.

In implementing self-protection measures, you want you to think about this. We are being asked as individuals in effect to become part of a widespread emergency response to this disaster. However, most of you on this call are part of universities and centers that comprise the AUCD network. And we also have

the capacity and the connections to amplify the response to this pandemic.

Here are some suggestions for doing so. First, many centers have been listing information and resources on their websites. This is invaluable for the disability community seeking additional information. At our center, we use resources that we had already collected from Hurricane Harvey two years ago as a base. And we were able to get our resource list up and running within about 36 hours. Including national, statute and local responses. Know that you are welcome to visit our site. Copy, paste, modify what you see there. Substituting information from your own states, of course, and just give us a little thank you. And the Cincinnati UCEDD did just that. Which I thank them for.

I also want to encourage you to maintain these lists. Because even after the COVID-19 emergency is over, unfortunately, new disasters will crop up. So, doing so will enable you to quickly update and populate your resources to reflect new emergency situations such as -- just as we were able to do.

Second, you want to connect people with disabilities and disability organizations with emergency management and public health contacts. I want to make this very clear. The way that emergency management is organized and enacted in this country is from the bottom up. Meaning from the county or parish level, then to a geographic district level and then the state. If your local emergency management office doesn't know about a communication need or a transportation need or a DME need in the context of this emergency, then they cannot resolve it. They cannot seek assistance from local government or the community. And they will not send that information up to the emergency management chain to your state to let your state emergency management know that, for example, a group home needs accessible transportation to a COVID-19 tests site or that the news station is not including an interpreter when they do their camera shot during broadcasting.

We must encourage the disability community to contact their local emergency -- office of emergency management. Or if we don't know where that is, local city hall with these concerns. It does limit the

good for us for disability organizations to only talk among ourselves in a disaster. We have to make that link with emergency management. One simple response to action that you can do is put an advisement on your COVID-19 page that quotes 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.

Your center could even provide a list of these contact numbers. Third, UCEDDs and LENDs employ terrific educators and trainers. Consider developing tools, services and supports that will further the work of public health and emergency management in this current situation. The chart that I shared with you earlier is a tool we developed just last week. We then sent it up to our Department of State health services and told them to feel free to use it, modify it, copy it, edit it, whatever would best further their work.

Another example is the REDDy Directory which we originally developed, again, in response to Hurricane Harvey with support from AUCD and ACL. We were able to copy that template, rename it. And as you see up on top, allow people to search for coronavirus resources.

And then we began to review which of the old resources were also available during this current COVID-19 emergency. We're happy to share this tool with you, by the way. We can send you the code. And you can populate it with resources from your own state. However, there are many other tools and resources. The AUCD network can be creative about in designing and providing to the disability community, public health and the emergency management community.

A fourth point is to protect the continuity of your center and its services. At some point this pandemic will pass. But what do you need to do now to ensure that your center stays -- staff stays healthy and productive during this time? Are there new programs that had you can create and office that will continue to make your center relevant in the current confection? And looking forward, what is your plan for rolling out services and programs that you have suspended once we have reached. Finally, the self-protection, social distancing and other measures discussed on

this panel also serve to protect you as an individual. And you're a valuable asset to the disability community.

Again, one day that pandemic will pass and we're gonna need every single one of us to restart research, education, programming and outreach activities that we have had to temporarily suspend. By taking care of yourself, you're taking care of the disability community because we're gonna need every single one of us on the other side of this disaster as we move towards recovery.

So, take care and take precautions and so that you can continue to do the important work that you do. Here is my contact information. I'm happy to hear from any of you and thank you all for the work that you are currently doing.

>> Adriane Griffen: Thank you so much, Laura. That was wonderful. Thank you, Dr. Stough. We want to quickly move along to our next portion of time. We have a couple discussants with us today. Hector Ramirez, if you are on audio, you are going to kick us off here. And then Lesley Cottrell. Hearing from two different regions from the country. Hector is from California and Lesley is from West Virginia. And then wrapping us up will be Dr. Steve Sulkes who will throw out a question that he has seen through a chat box. We have been monitoring throughout. So, we want to take time to reflect with you on what we have heard.

So, Hector, I will turn the virtual stage over you. Are you able to take the audio? Hector, it doesn't seem that you are connected to audio at the moment. We will come back to you. Let me quickly go to Lesley Cottrell. Lesley. I will let you take it away. Let me flip back to the slide. You can share your reflections, take yourself off mute and then throw out a question for the panel. Thank you.

I am not hearing you either, Lesley. Let's see.

>> Lesley Cottrell: Can you hear me now?

>> Adriane Griffen: I can hear you now.

>> Lesley Cottrell: Okay. Great. Thank you.

I was just saying that, you know, I appreciate the fantastic panelists. I think in many ways they provided unique information and the resources were absolutely fantastic. So, I'm sure we will all dig into

those when we get a chance. When we're able to download. I think a few things that I wanted to highlight from each one and then I had a few questions. One, Dr. Peacock, I appreciate her review of the etiology as we know it of COVID-19. We're learning new things each day.

Her task force sounds wonderful. I would like to have that in each state. And I think that helps us get the representation for individuals with disabilities for sure. And again, her resources were great. I apologize for going fast, but I know we're pressed on time. Dr. Yin, the sterilizing, the prevention of the disease is, again, important pieces. You mentioned additional care that I had not heard of in some of the general guidelines. And I hope they're added to the things that we send out to people. Some are daily, every day things that we do. But I just haven't heard of it before you mentioned it. And I appreciate you doing that. Dr. Holder had mentioned disruption of routine and focused a little bit more deeply on the adult portions of it. And as someone in pediatrics, I appreciated that perspective.

And the note -- the consideration of having someone with you in the hospital if you are showing symptoms is something that actually came up today. And floated it throughout our local systems. And people hadn't talked about it. So, I do think it's an issue that's just not part of the plan or once here in West Virginia and I appreciate you mentioning it. Telehealth is, of course, an option that we're going to. But additional training and offerings and resources, particularly for families and care givers is something that I think continues to be needed. You mentioned that.

And then Dr. Stough, you touched on nursing home assisted living which we hear a little bit about in terms of positive cases. But I don't hear about it in prevention from the general public and particularly the media. Thank you for focusing on those. Your resources were fantastic. The table is fantastic. I'm gonna steal it. So, I appreciate you sharing it. My questions, real quick. One is related to research and how do we learn from this? The other one is mental health because each of you mentioned it. And then final is next steps. So, I'm just gonna -- Adriane, you wanted me to list all the questions and then turn it

over or one at a time? What do we have time for?

>> Adriane Griffen: You can just open it up and see which one of the panelists would like to chime in.

>> Lesley Cottrell: Okay. All right. So, I'll start with mental health. One thing I hear from, and I'm gonna broaden this term to health care providers so it could include definitely nursing home providers, assisted living. But also, hospitals, staff. I hear a lot, and it goes to their mental health, about their worry about being additionally exposed at a higher level and coming home and either having someone although risk at home. Whether it's a child or individual with a disability. And they're describing stories where they're leaving shoes, extra clothes outside, they're staying in the garage, they're secluding themselves.

So, I wanted to hear if you have -- my question in that sense was whether or not there are guidelines for providers that either put them at ease that the guidelines of washing your hands and the standard that you reviewed is just as fine for them. Or if you have additional guidelines for the direct care providers. And bringing it home to their families.

>> Georgina: Hi. We do have some guidelines, from CDC, we have information for direct providers with considerations for infection control and things like that. Those are coming out soon. But what I would refer to you is some of the other kind of infection control guidelines that are already out there that maybe helpful. And maybe on one of these subsequent calls I'll be able to provide the links to that guidance. Thank you.

>> Lesley Cottrell: Thank you. Quickly the second question, I'm going to turn to research. And rather than a longer question I have down here, is do you think that we have representation from disabilities? So, the providers as well as the individuals and families in our research, in our understanding? Whether it's epidemiological, or clinical trials, whatever type of research you want to dabble into. Do we have representation of our populations in that work so that after we're set -- after everything is said and done, we can say the same prevention strategies apply, the same treatment options are available for all groups? And if not, what do we need to do? How can we get involved?

>> Laura Stough: The research on people with disabilities affected by disaster is really limited. And there has been some good small studies about children with special health care needs and how to get families to put precautions in place and things to do to support families with children with special health care needs in the context of disaster.

The most research has been done by actually psychology and psychiatry about people with pre-existing mental health illnesses in the context of disaster. And what that looks like, you know, particularly with respect to PTSD. I would say that typically emergencies and disasters do not create a large percentage of new mental health illness concerns. Much of what we're experiencing right now with anxiety or depression or fear is actually, you know, I don't want to use the word normalize. But it is a reaction that is -- is normal in the context. It is scary. It is anxiety-provoking.

The difference is if these feelings persist over a long period of time and then start interfering with other functions of daily life. Research from disaster researchers about disability has been very limited. Frankly, we're kind of the last to the table with respect to other marginalized populations.

>> And I was just gonna add that we are working -- we are gathering information on disability through the epidemiologic task force, I guess, in the response. So, on some of the case reporting forms and things like that, we do have some information that we're getting on disability. I will add a caveat to that is because there is so much going on, we typically get information from state health departments. And because there is so much that the health departments are doing right now, many of what we call the longer forms where people provide a lot of detailed information about people who are ill or who may have died, those are not necessarily being fully completed. And so, we are -- will need to go through the process of kind of going back and trying to get more data.

But we are advocating to have that information on people with disabilities gathered in our public health data.

>> Lesley Cottrell: Thank you. With that, I'm gonna turn it over to Hector for time. appreciate your responses.

>> Hector Ramirez: Thank you. Hello, this is Hector from California. I wish everybody well. You know, it's interesting to hear some of the comments. And overall, we have to remember that advocacy is part of wellness, of taking care of yourself. And nobody know this is better than people with disabilities. It's something that we have been doing forever. And now this pandemic has kind of really disabled society. Many folks are perhaps now aware of the difficulties that we face.

And now more than ever, I think society needs us. This is perhaps -- in my culture, we consider our purpose. You know? We're showing adaptation. We're showing that everybody matters. And we definitely have an opportunity here to make this moment and not feel so powerless as many of us feel. And, you know, I look at our captioners and our sign language interpreters and our providers and I look at them as potential service providers. Just like a doctor or something like that. Conversations are happening about taking away our rights during emergencies. People need to first ensure that we have the necessary communication tools and support for us to have better outcomes before they start talking about things like medical rationing.

You know, we do have significant challenges ahead of us. And this is really the time for us to all. Because our lives are in many ways are underlined. So, I think as we hear some of the conversations and some of the planning, we need to make sure that peers are part of the conversation. People with disabilities with lived experiences. Because a lot of states are having to deal with the situation at different phases and have different types of responses going. But coming from a state where we have really fantastic governor leadership and county leadership, we have been able to really start taking initiative, you know, all the way to early February. We saw this coming in January, and we started conversations.

And we had a head start. But we still lost people. And, you know? And we've looked to our neighbors. And we're standing together. And this is a time really for all of us to know that nobody's alone. That we are in all of this together. You know? We all of us have to be in this together, including people with disabilities. And that no one is going to be left

behind.

We've come too far in our space already. The ADA and some of the other laws, they haven't changed. Nobody has suspended those things. We need to fight for those. Speak up when you go for a walk, make that part of your mental health routine. That's what I'm doing. Treating, emailing, calling. That's all I can do. But I want to say that they need to be included. Not only do we have a COVID-19 pandemic, we have a mental health pandemic. But people with disabilities, we know what that feels like we can help.

>> Matt Holder: Hector, I want to echo what you said. Right now, when you mention the rationing and things like that, it looks like we're gonna make it through this first wave without having to face that. And what's good about that is we have time to have this discussion still. But we don't have a lot of time. You know, if we look at some other pandemics in the past, look although the Spanish flu, there were multiple, multiple waves of that, and I think the worst one was the third one. So, this issue may not go away. We may not be able to breathe a sigh of relief just because we make it through this first wave.

And I think what you're saying is exactly right. We really need people with disabilities to sort of help us, you know, and lead this charge. So, we can address these issues before they become a crisis.

>> Adriane Griffen: Thank you, Hector. This is Adriane. I would like to move along and ask our Q and A marshal, Dr. Steve Sulkes if he would like to take the microphone to throw out any last questions from observing the chat discussion. And thank you again, Hector. So, Steve, are you able to take the microphone? Not hearing you.

>> Steve Sulkes: You got me? Can you hear me now?

>> Adriane Griffen: Yes, thank you.

>> Steve Sulkes: Clicked the wrong button, sorry. So, I have been monitoring the chat box throughout. And listening to what all the speakers said. And the special COVID-related risks and stresses that we have been hearing about throughout this presentation are really well-taken. And what's come through in the chat box are that not only do our

speakers have a lot of great strategies, but so do our listeners. And we need to share a lot of the ideas that people have been putting up. Stuff about accompaniment, about adaptations for hospital and outpatient care. And we're, you know, in the fast-moving info environment that we're in, we need to pay -- we need to post those. And so, AUCD and other organizations can do this. And I think that's a point to take out of this.

Dr. Holder, Matt mentioned this very scary "New York Times" article with statistics about higher rates of infection and mortality for the population with I/DD. And I've also heard speculations that this population is not getting tested as much.

So, my question that I want to pose to the group is that good practice starts with good data. Do we know any more about special national data about COVID-19 in the population of intellectual and developmental disabilities? Do we have adaptations in hospitals and other care for the population that are working? And are states other than New York, as we heard about, coming up with accompaniment policies? I know that there has been some conversation about how data -- about this population being collected at the level of the CDC. Georgina, do you want to speak to that?

>> Adriane Griffen: This is, she went to another meeting.

>> A lucky escape for her.

>> She did. She will be joining us for our wrap-up webinar so we can follow-up to see her thoughts around data.

>> Steve Sulkes: My question to the group, we know about this in New York State about accompaniment. Have people seen success with accompaniment policies elsewhere in the country?

>> Matt Holder: I can't point to a particular state. I have seen a lot of discussion around it. It is on a lot of radars at this point. But I haven't -- I've seen a lot of complaints about it. But I don't know that I've seen a lot of -- a lot of policies coming out about it. And that maybe because a lot of people think that it's already covered under the ADA. But I know that I'm hearing a lot of complaints about the issue. So, clearly there's sort of a disconnect. And I

would think that just from an advocate sort of standpoint, reaching out to the American Hospital Association or sort of state-level Hospital Associations would be a good place to start for any group that is considering doing something.

>> Hector Ramirez: Can I add something?

>> Steve Sulkes: Sure, go. Go ahead.

>> Hector Ramirez: So, one of the things that I would also recommend people do. Every state has a protection and advocacy agency that works together at the national level with other states. And like disability rights California, work very closely with the national disability rights network. I would really encourage all disability organizations to reach to the one in their state. We definitely need to have a unified federal approach to this. We can't have really states working independently to piecemeal approaches. We already have federal laws in place. I think this might be both an opportunity to reach out and also to find some advocacy resources.

>> Steve Sulkes: Thank you. Adriane, can I toss out one more question?

>> Adriane Griffen: Yeah.

>> Steve Sulkes: Sure. So, there were questions about who could join the people in the hospital. But there were also some questions about people returning to day programs and when -- when we would know about that as a save thing. Maybe that's gonna get covered in a future session. But I think talked about how day programs in schools function for people to go back to them safely is a question that maybe -- maybe needs to be tossed forward to one of the future webinars.

>> Adriane Griffen: Yes. And that's a great note I think for us to wrap up on. Because we are over time. We are trying to break this out into more manageable nuggets and we're learning as we go here too. So, I want to thank everyone for joining today. Our next webinar will be taking place on next Wednesday, the 22nd. And for some reason I've lost the ability to forward the slides. I had a nice slide here saying the information. I popped it into the chat a moment ago.

It is going to be the afternoon of Wednesday, the 22nd. Please tune back in then. We will be

hearing perspectives from caregivers, family members, on how they are dealing with COVID-19. That will be an excellent time for information sharing and for further learning. Thank you all very much. This information will be archived on the AUCD webinar archive. We want everyone to be well, to be healthy. And remember, take some time to care for yourself. On behalf of AUCD and the National Center on Disability in Public Health, thank you all for your time and have a good rest of your day.