

AUCD  
Fireside Chat  
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[Live captioner standing by].

>> ADRIANE: Good afternoon and welcome. I'm the senior director of public health and leadership. It's my pleasure to welcome you today to a joint meeting of our emergency preparedness special interest group and our health and disability specialist interest group.

Today's session is a preconference for our annual meeting. And it's a little bit different than our other pre-conferences because we're featuring a panel that we're calling a fireside chat with leaders and health, disability, and emergency preparedness.

If you are not too Zoomed out, you would love to see you on camera, but we also know that you might need a break from the visual stimulation.

So it's up to you whether or not you have the cameras on.

We would love to know that you're here, if you wouldn't mind just popping into the chat a quick hello with your name and where you're from.

That would be wonderful.

I'm just going to go over a couple of logistics so you're familiar with how the session will flow today.

I'm going to make sure that folks are on mute.

[Background conversation].

>> ADRIANE: Please make sure you're on mute. Sorry about that. Just a reminder to make sure you're on mute. We will have question and answers at the end, so you will have the ability to mute and unmute yourself. It's a good reminder.

That kicks off into my logistics. Just wanted to go over today how this session will flow.

We have a number of wonderful panelists that I will introduce in just a few moments.

Today's session is recorded so that if you would like to go back and view it later or share it with a colleague, you are definitely welcome to do so.

We also want to make sure that when you are participating, that you are thinking about questions for the panelists. We'll have a dedicated question and answer time at the end. But feel free to use the chat function throughout to pose a question that you may have so that we have a robust question and answer time at the end.

And I apologize. I'm getting a little bit of an echo on my end. I don't know if that's from other speakers. Am I still coming through okay? All right. Thank you.

We are going to have a bit of a welcome from our leaders and liaisons for the two host special interest groups first and then we'll have an interactive conversation with the panel reflecting on the space we're in right now with COVID and the response to that as well as thinking through how this is a time to be creative and flexible and adaptive. There's no one size fits all approach for any of this.

So we'll have that in mind throughout our discussion today.

We have a wonderful roster of panelists that I'd like to introduce. And really, I'm just going to give the quick highlights of the hats that you wear and not get into too many specifics on your bios, as those are on our main conference website.

And I want to preserve time for our interactive discussions today.

We're going to hear from Ilka Riddle, associate professor at the University of Cincinnati as a director of the UCCEDD there. It's the center of excellence in developmental disabilities, and that's housed in Cincinnati Children's Hospital. Welcome, Ilka.

We'll also hear from Laura Stough. Chair of AUCCD's emergency prepared special interest group. Laura is a professor of educational psychological and assistant director at that UCCEDD, center on disability and development at Texas A and M University.

Welcome, Laura.

We'll also hear from Justice Shorter, or Justice. She's a disaster protection advisor with the national disability rights network. Welcome, Justice. It's great to have you back. I believe you were a panelist for us a couple years ago. Nice to have you back again.

Next is Erin. I'm sorry, Erin. Aaron Cignarale, if you want to correct me, that's fine. [Chuckling]. Sits in the emergency prepared specialist, Monroe County Department of Public Health.

>> [Background conversation].

>> Someone else needs to be on mute. Thank you.

>> You do have the ability to mute and unmute yourself because we are going to do questions and answers at the end. Thanks.

Next up we'll hear from Scott Greeson, who is the deputy emergency management coordinator in the city of Richardson, which is in Texas, and he sits in the office of emergency management. Welcome, Scott.

And then wrapping up our panel will be Vincent Siascoco. And Vincent wears a number of hats, assistant professor in the department of family and social medicine and in the department of pediatrics in the Albert Einstein college of medicine. Also the director of primary care at the rose F. Kennedy children's evaluation and rehabilitation center at the Montefiore Medical Center, which is affiliated with the university hospital for the Albert Einstein college of medicine.

That is who is with you. You're in good company. And without further ado, I'm going to just move us along here and turn it over to you, Ilka, for a few words of welcome.

>> ILKA: Thank you so much, Adriane. Good afternoon, everyone. And a very, very warm welcome from me from a cold Cincinnati, Ohio. We are really excited about this preconference session, and we are also excited to partner with the emergency preparedness specialist interest group.

As Adriane mentioned I've been the chair of the special interest group at AUCD for a long time and we cover a very broad spectrum of health related issues in our special interest group, and so today, we will really focus on health, health care in kind of, like, the kind of emergency preparedness planning response kind of a sector.

And yes, so welcome, everyone. We will have what we call a fireside chat.

So Adriane will ask us some questions that we will respond to.

We will have a discussion as a panel and then certainly, we will open it up for questions from you. We really want to hear from you about your ideas, your experience, and certainly also your questions.

So with that, I would like to give it over to Laura, if she is also to talk at the moment. I know there was a little emergency. So we'll see if Laura is on. If not, I will give it back to Adriane.

>> LAURA: Thank you so much, Ilka. Yes, it's so funny when you do research and presentations on emergency management, and then you have an emergency right before you present. But I think we've got it in hand now.

So welcome, everybody. And again, I'm Laura Stough. I lead project red, research and education on disability and disaster here at our center at Texas A and M university.

And as Adriane said, I also chair the emergency preparedness for AUCD.

In most states right now, emergency management is working hand in hand with public health in response to COVID-19.

In fact, in some states, including my own emergency management in fact shares that status at lead agency for response to the pandemic.

So our emergency preparedness special interest group as part of AUCD is more important than ever, and we'd love for you to join us. You can just look on the AUCD website under the issues tabs to join our SIG LISTSERV.

No, ma'am interested in hearing more from our panelists today. Thank you all for joining us this afternoon or morning, depending on where you are in your time zone.

>> ADRIANE: Thanks, Laura. Appreciate you. And I hope you stay safe where you are. All right.

So next, we wanted to have a bit of a conversation with the panelists, really thinking about how this is a highly adaptive time. Right? There's no one size fits all for anything we're dealing with now.

We asked each of the panelists to share a short reflection on perhaps a good idea or a silver lining in all of this and share that as a way to kick us off. It's a warm up to a deeper conversation.

And first up, I have Ilka, I actually have your slide up first for your reflections, if you wanted to kick us off.

>> ILKA: Absolutely. I'd be happy to, Adriane. Hi, everyone. As you can see on my slide, it has a little cartoon on it. And I will actually come back to this cartoon in a little while when we talk about some kind of great idea, different ideas that we have had.

So Adriane had asked us to start out with thinking about, like, silver linings. And I think sometimes, it's hard to think about silver linings when you're in the middle of a crisis or a pandemic and to see it as a silver lining.

But coming from a disability perspective, I think there are a few things I want to just highlight that I think have maybe helped us or can help us really in the future.

And so that is kind of, like, where I look at it in terms of a silver lining, fully understanding that right now, it might not necessarily look that way.

So one of the areas that I think we have made great improvements is in telehealth.

I think the response from hospitals and health care providers regarding how can we still provide good quality care to our patients without putting them at risk I think is something that has moved very quickly.

We also had health insurance companies move on that very quickly in terms of coverage of telehealth services. So some things were possible that I don't know if they would have moved that quickly without this pandemic.

And I think there are some definite benefits for people with disabilities in terms of having access to telehealth, which certainly isn't without challenges, but that's my silver lining, one of them.

I think the other one I would say is awareness and focus a little bit more on I think specifically adults with disabilities, especially adults living in congregate care setting and the challenges and the risks.

So you know that as a network overall, we are very concerned always about people living in congregate setting because they come with some challenges, and we have clearly seen this with a pandemic, how quickly something can spread in congregate settings and they may not be the best way to keep people healthy.

So having that spotlight on that would be the silver lining. Most certainly not that people get sick or that people die in those settings.

And then I think the spotlight on the right that people with disabilities have. Again, challenging because we talk about care rationing, medical equipment rational, but I think what that also has brought to light is great advocacy around the rights of people with disabilities and that people with disabilities have protection and should have those protections.

And we have seen the court system and the department of justice actually stepping up and making it very clear that they cannot be rationing based on a disability and that hospitals who have tried that, that that is not legally appropriate.

So I think for me, those are some silver linings. Again, awareness about the rights, being able to share people's rights with people with disabilities and family members and access to telehealth would be some of the silver linings coming from this pandemic. Thank you, Adriane.

>> ADRIANE: Thanks, Ilka. Appreciate you sharing that. And we'll come back to the slide in a bit for Ilka's other remarks as we keep going on the panel.

All right. Next, I had Laura. If you're able to talk, I know you were dealing with a bit of an emergency at home. If you're able to talk, I have your slides up. But if you're not, we can also keep going.

>> LAURA: We're ready to go. We're good here.

>> ADRIANE: All right.

>> LAURA: Do you have the next slide?

>> ADRIANE: I do, I do.

>> LAURA: What I wanted to share with you on this slide is just a sampling of the many hazards that occur here in our State of Texas. We have flooding, hail storms, we have tornadoes, hurricanes, wild fires.

And as a better of fact, NOAA estimates that Texas has experienced over 100 separate billion dollar disasters.

And in the 40 years leading up to 2019t that was included over \$250 billion of damages.

So a wide diversity of different kinds of hazards that that are very challenging and damaging.

And then here we come in 2020 with COVID-19.

So a silver lining, if you want to call it this, is that Texas emergency management is very experienced in dealing with different kinds of hazards, whether they be natural hazards such as storms or natural hazards such as the very small COVID virus that's causing this pandemic.

And yet the multiplicity of these different kinds of hazards make it really challenging and calls for the needs of different expertise and different disciplines to address these kinds of hazards.

So one way that we're moving forward in the context of COVID-19 is that our center is leading one of the working groups for public health and social sciences research sponsored by the university of Colorado at the Natural Hazard Center.

And together with a group of 14 scholars from nine universities and centers, our work group is -- has formed a think tank on issues regarding COVID-19 and disabilities.

And together, we are developing a series of papers around these issues. And that's being informed by the interdisciplinary approaches of these scholars.

And so we see great promise in continuing our work together over the next year in taking this kind of interdisciplinary approach to addressing this very sticky problem of COVID-19.

>> ADRIANE: Thanks, Laura. Appreciate that framing. Next up, wanted to turn the virtual microphone over to you, Justice, if you want to take the microphone and share just a couple thoughts around what might be a silver lining or, you know, a good idea that has emerged out of all of this.

>> JUSTINE: Hi, this is justice. Yes. I actually took a few moments when I initially heard this idea of a fireside chat, I said hmm, I wonder what my reflection will be on the day of because they're changing rapidly every single day and that's why I didn't put everything in one singular slide. But I'll share what is on my mind and heart today.

In terms of a silver lining, I think I have really been inspired and excited by how people are now starting to see the connection between racial justice and disability justice.

So we tend to say that you can't have racial justice without disability justice and you can not have disability justice without racial justice, and I think that has emerged out of the concurrent crisis happening right now, the pandemic as well as the crisis of police brutality.

It's been interesting to see the two worlds merge in ways that they were previously unwilling to do prior to 2020 and some of the uprisings and things I've noticed.

People are absorbing how disability justice really picks up where disabilities rights leaves off. So these two phrases are typically used interchangeably and they're not the same. But if you're curious about disability justice, you can go ahead and check out [sins invalid website](#), which includes ten principles they have created, and that is really the baseline that many of us that do disability justice work and disability rights work has -- have come to reference in terms of how to really guide and shape the work that's being done.

Among those ten principles, though, is a central principle, leadership principle No. 2. I think about that when I consider what has been done by way of emergency management and how people have managed to saved themselves and care for their communities and families throughout this year and also throughout, you know, decades and throughout our history more collectively.

But I think about mutual aid systems and practices that have been put in place. Communities just caring for one another, putting together groceries, filling in the gap that have not been met

by other programs and services and how those have really been absolutely central to the survival of individuals with disabilities.

When I think about different ways to solve the problem, I think of mutual aid, additional funding being funneled to the people doing work on the ground and that, of course, being inclusive and centering people with disabilities and organizations who center individuals with disabilities and those folks who are out there doing this work on the ground.

But I also think about a couple of other silver linings. The first speaker, I'm thrilled that she mentioned some of those legal remedies that took place. Right? I think about a lot of the legal action taken by the protection and advocacy network.

Many of the victories, a lot of shifts in tone and language that we see coming out of the Department of Health and also a lot of state specific departments of health have come by way of complaints that have been filed by not only protection and advocacy agencies but also many partner organizations who had been a part of that process.

And I want to emphasize that because it really focuses on the sheer importance of collaboration and working together with one another to kind of bring forth some substantive change. That happened because of the crisis.

You see it happening now in terms of vaccine distribution plans and how those are starting to unfold.

And as we think about those, I'm thinking about people with disabilities who are in all forms of congregate care or who are in carceral settings. Not just people in nursing homes, but also people in group homes, both licensed and unlicensed. Folks in psychiatric facilities.

What does it mean for youth detention centers, jails, prisons? Are we having those conversations? Because people with disabilities and kids and young people with disabilities are in all of those settings as well.

It's not about changing -- this is what I commonly say. It's not about changing your lane. It's about widening your lane. You have history or skill set in disability. Can we observe and absorb and practice that in all ways, especially as it relates to the multiple communities or identities that people with disabilities live within?

So I'm really curious to think about that. I think about it in terms of civil unrest and that was a concern a couple of weeks ago. The purpose of preparedness is to simply put things in place so that you kind of have a framework for how you can think about how particular populations will be impacted.

We were thinking about that. I also am thinking about how folks transgender will be impacted, transgender folks with disabilities impacted by crises in this pandemic. What does it mean for vaccine distribution plans that if there's ID requirements? Will people who are transgender or disabilities have to do with stringent practices that make it difficult or challenge their capacity to participate in certain emergency programs? I'm reading and having conversations with black liberation movements and trying to figure out what the course of action is there.

Because there are black people with disabilities. I want to know about undocumented folks. Because there's undocumented folks with disabilities. And I want to know what that means in relation to the work I'm doing.

Obviously, we should care about the community irrespective of whether or not the -- the disability does not have to be the primary necessity about we care about the community surely.. but as a black lesbian woman, I deeply care about the communities.

But going back to what I said before, you're not entirely switching your lane. Expert in immigration or you don't have to be an expert on black issues.

But you can share your expertise and knowledge related to disability if that is a particular competency you have and you can understand it through the prism of all of these other groups and have that strengths in your advocacy and strengthen the work you do.

I'm going to stop there, Adriane, and toss it back over to you.

>> ADRIANE: Thanks, justice. Appreciate that. I want to come back to you later and ask thoughts around how do you widen that lane [chuckling]. And I see that Brian Russel from Florida chimed in. Widening the lane is vital to our success. That resonates with others, too. Thanks, justice for being here.

Next, I'll turn the podium over to you, Aaron. You had a summary slide on what might be a silver lining or positive in all of this. I'll turn it over to you.

>> AARON: Thanks very much, Adriane. So I work in emergency preparedness for Monroe county public health. And I have a program that is called accessible preparedness.

It's the whole motto of it is it's not a one size fits all approach to preparedness.

And I was lucky enough that the silver lining is we kind of completed a lot of the first year, year and a half of this program and reached out to a lot of people with disabilities in different situations and different economic groups, different races, different everything across the board because it's not a one size fits all approach.

And we brought them in to do emergency preparedness training through a six-session course.

And this was right before COVID. We did this, you know, for the half the year in 2018, half the year in 2019. And then towards of end of 2019 we finished up the first cycle.

And I started doing interviews and videos with some of the students in the class a few months later asking them how they've integrated that training into their lives.

And some of them, you know, hey, this is really honest. They said, you know what? I took the class, thought about it, but I actually didn't do anything yet and I just -- I haven't actually, you know, started preparing for having extra food or supplies or medications.

But now that I talked to them and had the interview process with them, they started. And I've talked with a few of them and touched base throughout COVID-19, and the silver lining is that a lot of people from my class are doing a lot better through this emergency just in the short time from learning the basics of emergency preparedness.

They were able to have food on hand for that, you know, 14-day quarantine period. They started reaching out and building that network of people that they can -- they can call upon to help in times of need.

They already had -- when people started contact trace with them, yup, I have three people that can get me food, everything I need. I already talked with my doctor six months ago to see if I can get an extra week advance on some of my medications.

I know that's one of the really hard topics. Some of them were able to get the doctor to buy into that and say, okay, you can have up to six or seven days worth of kind of an emergency supply of your medication.

So in case there's a back log in being able to get you medication, COVID-19 really, really inundated all the logistics aspect of getting people's medical supplies. Obviously, food and everything, even just trying to get your Amazon gifts or whatever you're getting. All of that was slowed down.

So someone with a specific disability, they need this equipment, they need these medications to live. That's a really scary time. So doing this project just before COVID-19 ended up just happening to work really well and the fact that a lot of these people were able to not be impacted as much when COVID-19 struck.

And then there's also another kind of good idea that came from this.

Any time I taught this class, I also kind of start off saying, you know what? Even though I'm teaching the class, I'm not the subject matter expert on your disability. You're that subject matter expert, and you're going to teach me just as much if not more than I'm going to teach you. I'm really a facilitator to help these amazing ideas come across in the group so that we can help each other.

And I really learned so much about interpreting services, about different people's needs and disabilities, and really trying to advocate more and more in emergency management and public health to make sure that the message is inclusive of the population in our area.

In Rochester, New York, in Monroe county, we have a huge population in the Deaf community.

We have a national technical institute for the Deaf at RIT. And it kind of came up when we started doing contact tracing, a few people on my team were saying, well, how are we going to get this communication out?

And we already had interpreters for all the emergency broadcasts, which was not a thing that we had going on in the past. So that's a huge, huge benefit right there. [Dog barking].

When we started looking into getting an interpreting service for contact tracing, a few people from my team said, you know what? Why are we getting interpreters for such a huge portion of our community when we can reach out to that community and train them to be contact tracers so that they can have that direct connection instead of going through an interpreting service, and that idea has blossomed into having a few Deaf contact tracers that we trained through an interpreter.

And now, they're able to jump on a video call with people that have been exposed to COVID-19 and really have a conversation with them, really show them that you're having that conversation through the means that communicate the best to you.

And I think that was really important, and people have become more receptive in the community to being able to say, here's my contact, here's this, here's that, and really

understanding some more about education because we have contact tracers that can just directly talk with them.

We've done the same thing with some Spanish speaking contact tracers, and we've -- we've looked and canvassed for different groups where we can have someone that speaks that language instead of going through an interpreting service. That's one thing that really came out of COVID-19 and really tied in the accessible preparedness project.

It has really set us off in a good direction. Thank you.

>> ADRIANE: Thank you, Aaron. Appreciate that. And you got some nice love in the chat. Just wanted to give you a chance to observe that. Some folks are really appreciative of your adaptive thinking and the statement that you made -- I'm paraphrasing here, but something along the lines of being prepared to serve people with disabilities helps you be ready to serve the whole community. Thank you for your remarks. Appreciate you.

We'll hear from you in just a little bit in a deeper way. I'll turn the virtual podium over to you, Scott, to share your thoughts on what might be a positive or a silver lining in all of this.

>> SCOTT: It's such a hard thing to say silver lining on such a tragedy. But we're able to get some valuable lessons learned.

Items we had in place, in Richardson, we're a small jurisdiction, probably population of 150,000, but we have a unique location within Texas that our surrounding areas heavily populated. The city of Dallas, and other cities, a population of 100,000.

We were able curious about, you can collaborate more than anything. We had preparedness out there.

We always hang our hat on preparedness. We call it empowerment. We really want to empower the people who need it most, people with disabilities, people with service needs more than anything.

I know Aaron just talked about the Deaf. We have large Deaf community in our area as well, and speaking with somebody that was in one of the associations there, she wanted to express the empowerment because it was a misnomer -- and I think that's just not with the disability, but most folks, when things happening at the State or the feds will rush in and be there to help you with everything.

That might be true to an extent. Might take time of course but there's things they can do themselves to help themselves. Having that handy for seven days. And people see the value of that empowerment.

The other thing was the collaboration. And I think justice talked about the collaboration. I was shaking my head vigorously because the collaboration was key for us.

We had so much information coming in at such a short time. Conflicting information, and God bless these long term care facilities and other care givers having to try to assimilate this information. It's almost like drinking from a fire hose.

What we were able to do was bring together public health and fire department that runs our EMS program and create a committee that would work with these long term care facilities when we got notices that they had positives to help take the scariness out of it.

Provide information. Hey, this is what is expected of you. These are the resources we can provide.

One of the things Texas did -- I think it was a good idea to a point but -- and I'm sure Laura can tell you this as well. They pushed out state of Texas assistance request. These people never filled that out in their lives.

So much information coming at them. How can we break this down and enforce the partnership we have? In Richardson, we have a care giver association, work with long term care facilities to review plans, give them ideas on things to think about.

Even exercises, nothing beats a real live operation to build those bonds. We were able to build the bonds. Able to go into the long term care facilities and break the information brown, and then give them plenty of resources to kind of help them get through the issues.

One of the things -- it kind of spread through the state was create task force for testing to be able to quickly go into these long term care facilities. Not very complicated to maintain the sanitization there and hopefully limit the spread.

Those bonds have been great. The collaboration has been absolutely wonderful, and it's reached out. We had a healthy amount of care givers and long term care facilities. I would easily say it's doubled now.

It's really been a blessing.

Other thing is we were able to put other operations in place. Unfortunately, we had hurricane Laura which is unique because now, the typical use of the congregate shelters had to be pushed to the side.

What we found and -- actually too, our relief, the non-congregate shelters worked better than our congregate did. It empowered people, had privacy, they were able to recover quicker, believe it or not.

We still had issues where people needed special equipment, the medical equipment and what have you. We had a healthy list of medical equipment, special needs equipment and some other people maybe were not finding the equipment because maybe they had only one, or two or three divider was on the list. But the point was we were able to get it.

We were able to reach -- an individual reached out to our mayor. Disability task force, it was road blocked. It was one time we could not find equipment. Talk about collaboration through that particular group, I was able to address the needs. She had a son needing breathing equipment, and we are talking about the medical providers putting limits on -- as far as supplies and what have you. That's exactly what happened with this young lady.

So I was able to reach out to Laura. She was able to spread it through the group. Amazing. Absolutely amazing. People were able to reach out to her and get that problem solved.

But it's the collaboration, right. It's wonderful, but also with our non-profits. There's so many things we were able to accomplish through this -- and still accomplishing through COVID. And I think it's going to set the template moving forward.

Do we have problems? Most definitely. And some with our state facilities, limiting information that's coming out. But I would just say that for the most part, it was a huge success, at least in Richardson.

>> ADRIANE: Great. Thanks, Scott. Appreciate you, sharing those remarks and reflections with us. Next, I want to turn the virtual podium over to you, Vincent. I'd love to pull up your slide here. I know you said you had a couple positives or silver linings in all of this. Let me go back to your slide. All right, over to you.

>> VINCENT: Good afternoon, everybody. A quick background, I'm a family physician here in New York City, also working in the nursing care world for several years. In addition to my role at chief medical center [audio cutting out] of New York City that provides services for [indiscernible] facilities. We provide services close to 67500 individuals throughout the area and provide services to those individuals -- probably 30 to 40 disability agencies throughout New York City.

On a larger scale, throughout New York City state, I'm sure Aaron knows this -- we talked about coalition and collaboration. That is so key.

Here in New York, across the state, there are about seven major developmental disability coalitions.

They provide services to close to 250,000 individuals across the New York state. They represent about 300 plus different disability agencies from the Bronx to Niagara falls to buffalo. The New York City disability advocates, the logo is there. Some of the silver linings, talking from the Bronx and New York City, we were the epicenter of the epicenter. We were the ones hit the hardest and quickest.

It was overwhelming for sure, but what was really wonderful were the coalitions because we were all there for support. Interagency councils, Cerebral associations were just two of the many. The information was coming so fast and furious.

It wasn't sure what to believe, what not to believe, how to take care of someone in your group home. They have to be quarantined, isolated.

Here in New York City, they closed down public school system, largest in the nation.

And then March 17, every day program. Our each of our health center connected to day programs. So March 17, we were a ghost town and totally cut off from our individuals.

So these DD coalitions were our connection to those individuals in the congregate settings and those in the community.

So we were all sharing information. So these DD coalitions will have anywhere from 10 to 15 committee members at a time, once a month. They were over 100 people on the Zoom meetings and everyone was so helpful sharing information.

One of the things that came out of New York was the data that we shared, you know, shared among the different developmental disabilities agencies, information on congregate settings, the individuals. Not only individuals but also staff. So that data was really key to bringing that to the advocacy level to make the state aware of the needs of our patient population.

Not only of the individuals, but also the DSPs, also the staff that were working in the group homes.

So I think the data that we shared -- and some of you know that contributed to a couple of articles in the New York City Times. There was a couple of research [indiscernible] that came out of the [indiscernible] university that shed light on the need for care for our patient populations, PPPs for our staff.

So coalitions, collaborations, communication is so key. That's a common understanding. I mean, that's kind of a no-brainer. But what came out of it was sharing data and the ability to raise awareness and approve upon advocacy and being asked to come to the table and talk about your patient population.

I think here in New York City and New York state, unfortunately a lot of the nursing homes got hit. And the spot light was on them.

Rightfully so, but also the congregate settings. Telehealth is the way of the world nowadays. It was a life saver. And I think the regulations because of COVID -- and I apologize, I know the speaker said this before, but if COVID never hit, we've always wanted to provide telehealth.

My clinics are in the urban areas. So based on regulations we want to provide telehealth, but there were no regulations. That was a challenge.

When COVID hit, the regulations eased up, we were able to provide that. One of the things that we unfortunately had to make a decision on our health center was to close certain sites and furlough staff. We furloughed 50 percent of our staff. It was very difficult.

So the ability to provide telehealth, quality of care for our individual, make sure that we can pay our bills, keep people employed and working was key.

So telehealth was a god send. It's not be all end all. One of the challenges, of course, is what can you do with telehealth and what can you do on site? Telehealth shouldn't take the place of a face-to-face visit in some situations. So I think that's a learning process that's going to be for all providers.

But I think telehealth was just a real [audio cutting out] especially when we talk about behavioral health issues and mental health issues that came out of it. Are psychiatrists and clinicians, psychologists, social workers, almost 100 percent telehealth and we're able to maintain that connectivity for behavioral health, stress, anxiety. I think that's important.

Here in New York, we have 12 regional informational organizations. I'm sure they have it in other states. But this concept has been around for a while now, the idea to have hospitals and practices and clinics all [audio cutting out] quote-unquote and share data. It's not a perfect science, but probably a year before COVID hit, we connected with our RHIO in New York City.

And we were able to work with a platform called Azarro [phonetic]. And we were able to put together a report that can see any of our patients that were hospitalized at any hospital in New

York City, get their name, their date of birth, which hospital they were seen at, when they were discharged and date, when patient had or didn't have a visit with one of our providers.

This was prior to COVID. This was so crucial when COVID hit because we were cut off. However, we were able to utilize this report because it was still running.

So my office is based in the Bronx, so we were all hunkered down in the south Bronx. But through this, through the organization and the report, we were able to see, okay, we have two patients from a group home on Staten Island. Let's get set up for a telehealth visit. Someone was hospitalized a month ago and discharged. Let's set up a visit.

The silver lining is the telehealth connectivity, a great blessing for our patients and for us to make sure that we can continue providing care as physicians. Thank you.

>> ADRIANE: Thank you, Vincent. I really appreciated your point around connectivity for staying in touch with those who have co-occurring conditions and dealing with all of the pieces of telehealth around that and echoing the points around coalitions and connectivity in that way, too. Thank you.

That was a great way to wrap up that first chunk of conversation with the panel. But that was really just a little bit of a warm up. [Chuckling]. We are going to go a level deeper now and talk about how we want things to be different. What do we want to change?

How can we be creative and problem solving at addressing these challenges that we've all just mentioned. So I'm going to throw that question out to the panel.

And I know a couple of you had some specific thoughts around that. I want to circle back to you, Ilka, to see if you want to kick us off and perhaps use your other slide. I'll circle back to that if you want to kick us off.

>> ILKA: Thank you, Adriane. I think it was interesting to hear from so many about the amazing work that has happened.

I think if I kicked us off in terms of what would I like to see changed or what should be different, I think one of the things that we have seen and that might not be that great is that there's a lot of attention surrounding an issue during kind of like the crisis and maybe right after the crisis.

And then there are all kinds of plans that people talk about in terms of we need to put this in place, we need to not forget about this when this is all over and we need to address it, and then time moves on.

And all the things that we've talked about in terms of not wanting to forget are forgotten because the crisis, the pandemic, the storm is over and we are back to our normal lives.

And I think we have to really try to continue our collaborations to continue to really think about, okay, let's not get back into this kind of pandemic situation ever again.

So how can we make sure that we prepare better and that we prepare appropriately for people with disabilities and other marginalized groups?

And how can we get that into writing? And not just into writing in a protocol or a guide that sits on somebody's shelf or desk that may or may not even be pulled out at the next crisis, but how

can we really integrate that into our thinking, framework, practice, so that it just becomes part of standard practice, part of standard preparedness planning management?

I think those are the things that I would really love to see changed because I think we always have great intentions but so far if I look back to other emergency situations that we've had, it didn't unfortunately lead to a better practice the next time around.

And so how can we take what we have built during this crisis, during this pandemic in terms of relationships, in terms of collaborations, and how can we work together to integrate it into frameworks and practice? That's really what I would love to see change.

So that -- I think earlier in the box, someone talked about universal design. Let's take a whole kind of universal design approach to all of this and make sure that it includes all groups.

I think -- so that is one of the components. I think the other component that goes well with what Aaron is doing, in terms of empowering people with disabilities to be their own advocates and to prepare for themselves and to be prepared so that they don't depend on a system that may or may not have thought about all of their needs. Right?

So how can I with a people with disabilities, how can I have a family member make sure that don't depend on others to come to rescue me from my house?

I think those are the things in terms of what I would like to see changed. In terms of what COVID has kind of, like -- how COVID has impacted our work and had to do something different than what we originally thought about -- and this is why I have this slide up here -- we had actually just started working on an emergency preparedness project before COVID hit.

And one of the components of our project was to bring together emergency responders, emergency planners and managers with people with disabilities.

And we had planned, like, two events so they can kind of get to know each other, talk with each other, learn from each other, hear about these are our needs, those are our needs, and, you know, have this conversation.

COVID came, and obviously, those in-person meetings were all cancelled.

So we had to think about, like, what can we do now? So what we did instead is something that I think, you know, we now can use long term because it's not a one-time kind of thing.

We collected feedback from all of emergency personnel on what do you feel like you still need to know or you need to learn or what are the questions that you would have for people with disabilities?

And we collected all of the information that they shared with us. And we did the same with individuals with disabilities and family members in terms of, like, okay, if you think about your needs in an emergency in a crisis situation, what questions do you have or what do you need or what do you want to know? And we took those answers and questions and created a little -- we're in the process of actually finalizing these two cartoon videos that will be available on YouTube to everybody.

And we will promote them to our emergency partners. That kind of took the information and put it into a little kind of, like, cartoon that people can watch that is fun to watch and engaging

and hopefully we also hit kind of our diversity kind of component as well in that video, and we're answering those questions.

We're answering the questions for people with disabilities and their families as well as emergency planner, responders and managers.

We kind of used that as a substitute for our two-time kind of, like, events.

And I think that just gets me to the last thing that I think we sometimes forget and it's so important is that all emergency response planning is local.

So you really as a person with a disability or as a family member of a person with a disability, go and find your people, go and introduce yourself and make sure that they know you and you know them because if they have a personal relationship with you, they will not forget about you because they know that you, John, are there and you will need their help.

Or I think we sometimes forget that. And everything that's local means in some -- somewhat in our control because we can establish those partnerships or those relationships.

And you know, I'm just sharing kind of a personal story just as Laura had an emergency just now, last week, my son had his first seizure. We've never had one, and I had to call EMT, and we had never dealt with any of this.

And the positive thing about this is now we know some of the guys from the fire and EMT station and, you know, we have this established relationship with them. And I wish I would have had this before hand, but I'm glad that I got the opportunity, you know, to establish that now.

I think in those ways, too, I think sometimes we have the tendency to think abstract or on a framework level or on a higher level, and some of the things, we can do ourselves on a very local, individualized level.

And I think with that, I'll push it back to you, Adriane.

>> ADRIANE: Thank you so much, Ilka. And I appreciate you sharing your story as well. I think that's really important for us to keep in mind, you know, that it's an emergency. Things happen. You never know. So thank you for that.

Next, I would like to use the moderator prerogative here and move up to Justice to share remarks because I know that you had to jump off a little bit early. And I want to make sure -- I'll flip back to the general slide here. I want to make sure you have time to reflect with us on these key questions for the panel around what do we want to see changed? What do we want to be different, and how can we be creative in problem solving to address these challenges? So Justice, would love to turn it over to you.

>> JUSTINE: Hey, everyone. This is Justice. Yeah. I'm going to do something a little bit differently here. I want to start by acknowledging some of the people on the call who do this type of work. Not by name, but by way of experience and some of the things that you have to continue with on a day-to-day basis to do the work that you do, whether it be specific to emergencies or public health or education or with regards to how you show up in a space in terms of the multiple roles and responsibilities that you have.

And sometimes it can be so difficult for us to understand and accept that we can't do everything, right? And then that could be really difficult because there is just so much to be done.

I think about that in terms of concurrent crisis. We want to jump in and do the best that we can, but I also want in terms of things to change. I want us to understand the importance of sustainability.

And I think Ilka was talking about this before. We don't want things to sit in the plan, just happen one time. But this also is important with regards to how we can sustain ourselves to do this work long term, right.

So we know that the ramifications, the impact of these crises will take years and years to deal with on top of still having to deal with sudden crises that still emerge.

Structural violence, slow onset of emergency, slow onset emergencies, it's a whole thing I won't spend a ton of time talking about now, but I want to emphasize and affirm that experience for many people on the call and acknowledge that it is sometimes okay -- actually always okay to set boundaries for yourself.

I was listening to a pod cast -- again, listening to different things to open your mind and get a better sense not just personal growth but professional growth.

A wonderful woman said a quote around boundaries that boundaries are the distance between loving you and loving me simultaneously.

What that means is the distance between loving your communities, loving the work you do -- and I'm talking about this in terms of this context because she was talking about this in movement work. But I'll mention this in the terms of this space, how it can be applied.

The distance between loving the people you're here to serve with, connect with, the distance between loving them and loving yourself, too. You're also worthy of time and space. That love can be exemplified in a number of ways. Exemplified in you showing up to meetings multiple times a week or once or twice a week.

It can show up in you physically being out there or from your bedroom or living room. That's the bulk of your capacity for that moment. That's taught clearly in disability justice.

I want to address. We hear take care of yourself, self care, but we don't talk about that enough of what that means. So I wanted to acknowledge that for a couple of folks on the line.

A couple other things, here. Ilka mentioned that we want to focus on empowerment, that we want to put in power people with disabilities, in power, in positions of power. And what that means is there's a wonderful guy named Rashad Robinson, executive director of color for change.

He said presence doesn't equal power. Presence doesn't equal power. We mean the ability to change the rules, regulation, change how decisions are being made.

So we don't want people with disabilities to just be casually consulted every now and again and everybody goes in the back room and they make the final decision on what's happening. But the public leadership team, is that inclusive of people with disabilities? And more

specifically, is it inclusive of people with disabilities who want to use their experience to inform the work you're doing?

Not everybody is black wants to inform the work. It's important to think about that. I say this purely out of experience where people say, well, we have four people with disabilities and yet their plans have no mention of disability. So I want that to be clear when we talk about putting people or pointing people or advocating for people with disabilities to be in positions of power.

Want to acknowledge interdependence, which is one of those disability justice principles. I know so often in emergency management spaces we talk about being able to save yourself independently navigating, individually be able to solve problems and get out.

But I want to affirm for the people who do not have the equipment or the services or the supports to make that possible and how interdependence is such a vital part of that survival mechanism for many people. So I want to acknowledge that that's really important as we think through.

And I say this because sometimes people will tell me, you know, they recommend a go bag that I don't have the money to fill. I can barely fill my own cabinets, my baby's stomach. And they're talking about a go bag. I'm already rationing my medications.

I don't have money. I don't even have insurance. There's a lot of barriers to people's experiences, and I just want us to be mindful of that as we're making recommendations for what people can do to prepare. I want that to be a multi-faceted process.

We're coming forth with multiple ideas, strategies, and processes to meet people where they are, wherever they are. And that may be different from the main stream experience.

So I just want to kind of think about that a bit.

And then the last thing that I would say here, I know there's this real push and expediency in getting back to normal [chuckling]. Let me say that normal wasn't necessarily great for many people before hand. So getting back to normal, I want us to get to a better place. Right?

I don't want necessarily go back because there's people with disabilities who have been fighting for the accommodations that have been made available during the pandemic. They've been fighting for those things for years and denied repeatedly.

In terms of work, for example. We give people these different ideas in terms of what to do in to prepare and people may not have the monetary means to do that. So you're talking about people working and some people are over qualified, underemployed but who have been trying to get certain work accommodations for years and have been denied.

The very same accommodations that are being made widely available. I'm working remotely as we speak, the ability to shift and flex your work hours, things of that nature. All of that is important. So I hope that those accommodations continue throughout.

And I hope that people continue to collaboration in terms of the network work that's being done. And I can specifically talk to NDRN.

The protection and advocacy network were able to have rapid an and robust response because legal directors, CEOs were talking to each other. They were sharing some of the

language they were using to get these complaints going. No personally identifiable information of course. But we chose this strategy, that method, that seems to work good in that state. We didn't have to file a complaint because they said this, and they immediately so what we were planning to do. They chose to change the course of action and recognized how disastrous of an impact this would have on people with disabilities. There was sharing of information also certain strategies such as getting web pages up.

And having additional means of folks contacting and filtering in information to the PNA. Not just social media that was really heavy but then also having email addresses being posted because not everybody, you know, has the bandwidth to fill out long, complicated forms.

Or has the ability to call in and talk extensively for a full blown intake process, but providing that information via email, text. Additional ways for people to be in community and conversation and inquire about help and assistance.

I will mention all of those things, and I will stop there. I can go on about this for hours and quite literally I do when I'm doing presentations. But of course I have to stop. I have to jump off in a few moments, but if anybody has any questions Adriane has my contact information. Be more than happy to continue the conversation.

I don't know if you're tweeting or anything like that, but if you're on the social media buffs, I'm not but I try. I'm on Twitter, but just a shorter one. Thank you so much.

>> ADRIANE: Thank you, Justice. And I just wanted to say a couple things that resonated with folks in the chat was your comment around normal, what was that about? [Chuckling]. Shout out to Emily bridges. She just had an awesome quote in the chat. Normal is a setting on a washing machine. I don't think anybody wants to be that. So it resonated with folks here. Thank you, Justice. Whenever you need to head out --

>> JUSTINE: I'll stay for a few more in case there's questions.

>> ADRIANE: Linger as long as you can. Thank you, thank you, thank you.

So next, I'd love to invite Aaron to the virtual podium to talk through what do we want to change and what are some thoughts around how it happens and how we might be creative in problem solving and addressing these challenges.

>> AARON: Definitely. Like justice, I can probably talk about this forever. I'll try to keep it short.

What do we want to change? Some of the main things that pop up to me is just more inclusion in that training exercise and response area.

You can't really train, exercise, and respond to the whole community unless you invite the whole community to the table.

So I think a lot of times in emergency management, emergency preparedness, public health, whatever government agency it is or public agency, it really doesn't matter -- or private agency. I think a lot of times, we try to think, okay, well, how do we hit the ADA guidelines here? Or how do we include this set of the population?

And there's a bunch of people around the table, you know, maybe discussing this briefly on what they think, but you don't have an actual advocate there to say, this is what it's really like.

I can sit here and tell you what being in a wheelchair is like and how hard it is to travel and to get into places and what the ADA guidelines say that, you know, setting up a shelter or -- how much space you need.

But actually talking to my friend who is in a wheelchair, she just blows my mind with all the things I would have never thought of. And that's what we need at the table.

And I love the whole presence does not equal power. That's an amazing quote. I'll definitely be using that, justice, for a while, just because we invite them to the table doesn't mean that we're giving them the power to do anything.

So what we need to do is not just invite them to the table, but put them in charge of these decisions, give them that authority, give them a clear guidance of, okay, we want you not just to, you know, check a box saying we had you here and we included some of your ideas.

We want you to work this issue with us. We want to reach out to the community to help get this on board. And we really need to try hiring people to be in those positions of power so that they can sit there and safe, okay, this is what we really need. Let's make it happen. Let's get a team together to make it happen.

That's obviously a lot easier to say than to do, but that's a huge area that I think we need to change and we have to start at the baseline of, you know, asking those questions and getting people included into the table and start to give them those positions, start to give them that authority to make the changes to emergency plan, make the changes to our exercise.

And just from my own personal experience, I love training as real as possible [chuckling]. And they put me in charge of volunteer management for points of dispensing and some emergency management mass casualty things. I went to the senator of disability rights and said, hey, how many people can you give me to come and do these trainings?

So we actually had people that had mobility issues. We actually had people that were Deaf so that when the fire fighters went over to people that were injured, you have somebody signing at them and they don't know what to do. You're putting them in the actual position.

You can't just put a card that says you are Deaf, act as if you don't know English. It's not the same. It's not the same to say, okay, put another person into a wheelchair. No.

It doesn't work. You have to go out to the community. Honestly, you can make it really fun.

And they really enjoyed being a part of that exercise. And honestly, it was a wake-up call I think for a lot of people and you can't be worried about looking bad because looking bad is the first step to figuring out where your gaps are so you can start working on them.

And as much as they were, like, wow, the interpreter was really horrible that you guys had this point of dispensing and didn't really know Spanish too well.

We had feedback of this is not really an accessible point of dispensing. It was really difficult to get through. You know, you think that it's just a negative, but it's really not. If we're training and exercising realistically and including everybody in the community, we're going to learn a lot

more, and we're going to be able to actually make a difference so that when it comes to a real event like a COVID vaccine dispensing, we're going to already know some of the tips that we didn't hit during some of our exercises.

So that we can actually help them in a time of need.

Also, what do we want to change? Communication, oh, my goodness. Communication is so huge.

I've tried to explain to some people that just really didn't get it how having a sign language interpreter on the screen is so helpful, being able to have closed captioning is so helpful.

And how sometimes closed captioning is really, really not -- it's not saying the right message. So there's a difference between someone actually there being able to do the closed captioning or trying to say oh, this automated device is going to be good enough.

You don't want good enough if it was you in their same position. So we need to help people kind of understand. And that's all about being included.

For COVID-19 related, how do we get that education out to everyone? We're struggling with it in our county just trying to figure out, okay, we put this education out there, but it's really only hitting a specific group of people.

How do we get on TikTok, Instagram? How do we formulate the message that it's easier for people to understand with obviously different education levels, different backgrounds?

We have to put it out in different ways. One thing I've been doing with a lot of people is I explain viral load as everybody has a cup and everyone has a different sized cup that their body can take before they get sick.

And I try to explain it saying, you know, when you're walking by somebody for two seconds that has COVID, it might be two drops into your cup. It's not going to overflow. It's going to reach that capacity.

When you sit down with somebody without a mask on, now it's like pouring water into that cup.

Well, if I have -- maybe I'm immunocompromised and I got a little thimble, I've got a little Dixie cup and somebody else next to me has a big gallon jug of water that they can fill up, that's why I'm going to be at higher risk.

I'm going to have my cup filled, overflowing first, whereas that person, he'll walk away from the conversation and never get COVID. And even that quick breakdown of trying to help people understand it, it takes it out the medical jargon that kind of goes over people's heads.

And it makes it like, oh, okay, that makes sense. So we need to do more TikTok videos or little video clips. It's got to be funny, something that can be light hearted that people will want to watch and say, oh, that -- okay, now it's clicking, making sense.

And I think that's something that's something we need to work on.

Some of the creative problem solving things we've done, we obviously started training in that direct language.

Trying to get a primary connection instead of going through an interpreter.

We've used different mediums for technology, such as Dropbox, fillable forms, Google voice to not only call people but to text them as well.

And volunteers that had a disability, whether it's hearing, mobility, medical, we've had people that -- I had one guy that was volunteering and he's going through cancer treatments, but he wanted to help the community, and he said there's no way I can come into the building to do a training, so we use technological solutions to be able to get him hooked up with Google voice, be able to help him train in a way that made sense for him.

And we do have some contact tracers that are volunteers that they're hard of hearing, but we still want them to help.

So they're our texters. They sit there on Google voice and they're typing and texting every single person to try to give, you know -- get in contact with people. And they pass that information on to people I can call.

So there's lots of ways out there, and we have to kind of figure out how can we think outside the box?

Technology right now, I think this is -- we're poised for the best, like, explosion in using technology ever to meet our needs. And I think most agencies that weren't receptive to technological advances in the past, mostly government, are now really adopting technological solutions which starts to really include the community.

I'm sorry for talking so long. I can go on for a while. But that's what I have.

>> ADRIANE: No worries, Aaron. And thank you. That was terrific. That was really helpful.

And I may follow-up with you to flesh out that cup example. I think that is so helpful in terms of making it real for folks who, as you say, some of the techy medical jargon is just not going to resonate.

But you can picture, do you have a thimble or a gallon container for the exposure? So thank you, Aaron. Appreciate you sharing with us.

Next up, I would like to invite Scott to the virtual podium here to share your thoughts on what needs to change. How we can get creative in problem solving in addressing the challenges?

>> SCOTT: Aaron pretty much stole the thunder there. It's good EM's think alike on this thing. I feel empowered to have like-minded people here.

Communication is key not just for COVID but anything.

I think sometimes, we limit the way we deliver messages out to the public. Maybe using one, two, maybe three different methods, but it's got to be a multi-faceted approach. I think Aaron hit on this grade. We need to use every tool in the tool box.

We have the standard flat head screw driver, pair of pliers, a hammer, but that will be good enough for some people. But not for others.

We need to find out what's worked and there's still lots of people we haven't reached.

We talked earlier about widening that panel. How do we reach these particular folks? I think there's several ways. Again, look at what we've used and see how -- what other mediums we might be able to get. Maybe it's associations, chat groups, I'm not sure. But we really need to have a good look at that.

Ilka made some great points, too. I was standing up, jumping up and down because she knocked it out of the park as well.

We need to engage the community more. We do have a decent job, but even a good operation can always be improved upon. And we have to be honest.

I've been through so many after actions where people aren't honest with what's happened. Aaron knows this, anyone in emergency knows this. People hate to say we made a mistake. But it's okay.

We don't want to bring people in because we don't want to expose, hey, we don't know. But we want to bring people in that can give us the answers. That's absolute craziness here.

Talk about building trust in the establishment we may be able to do that with our long term care facilities. And like I said, our participation with the has almost doubled because they can trust us know, they know we're all for their benefit.

We're not there to report them, our looking for mistakes. It's how can we as a group get through? Your success is my success, your mistakes are my mistakes, et cetera. We need to continue with empowerment, broaden the way we deliver the messages.

I think Justice made some great points. There's lots of people. I want to the poor sections of the county sometimes. These people didn't have money to put things together. What can we do? There's plenty of grant money out there. We just have to dig a little bit.

Ilka made a point that we can identify this. One of my mentors used to say -- had a joke about turkeys and eagles. Taught the turkeys that was great and then everybody walked home. We talk about this thing. It sounds really great, but we never enact it.

We have to identify what the issue is, identify the solution. Put a date on there.

Who's going to be responsible for it? Document it and make sure that everyone can follow-up with it. If we do that, we'll be more progressive. In A and M, we have the worst ability to table it or put it on to a committee that sits there for a year and never ever happens until an event happens again and we see the same issues repeating itself. It's the definition of insanity.

So I think there's a lot of good input, a lot of things we can do as a group out there. We need to address them, be honest about it, try to find other ways.

We've been good about engaging people, but there are people out there that still need to be brought into the fold. How? I don't know exactly. If somebody has ideas -- I have no ego, please give them to me. I'll take whatever I can. That's all I've got, Adriane.

>> ADRIANE: Thanks, Scott. I appreciate that. And I wanted to also reflect on a connection that I see between what you said about being honest and what Justice said earlier around, you

know, loving yourself, loving the community, being passionate about the work, but also setting some positive boundaries.

I think being honest and the after action report is important but it's also important to be honest with yourself and drinking from the fire hose, you know, the information over load, that is an analogy that I have also used in other presentations over the last few months. And you need to take care of yourself because these issues and emergencies -- they are emergency du jour. It's what is going on right now.

There's going to be other things, and we need to be here [chuckling] to address that.

And serve the communities we serve. So right on, thank you, Scott. Appreciate you.

Next, I'll like to turn the virtual podium over to you, Vincent to share your thoughts on what needs to change, thoughts on ways we can be creative in addressing challenges.

>> VINCENT: Thank you for allowing me to follow all these wonderful speakers. It's not too much pressure [chuckling]. I think these are great ideas and just insights.

You know, I guess on my end, what do we want to change? Just have more proactive engagement.

Speaking from my end of the world, I see a lot of these, you know, after the fact New York City department of health committees, hospital committees, now they want to get the IDD input. They want to see what could we have done better? What can we do moving forward?

It's interesting because they'll invite the docs, the administrators, what have you, but I don't see any individual advocates. I don't see anybody representing their own selves, you know, or being invited to the table.

So I think engagement is very important. Making sure that we improve community engagement.

When I talked about the [indiscernible] in New York state and how wonderful they are, they're wonderful but I think some of the challenges are some of the community coalitions and connecting the two.

So when I talk about the DD coalition of New York state and New York City, they don't actually mesh well with the non-DD coalition on Staten Island. Not because they don't mean well, but there are certain challenges.

For example, food and security, what have you. I was on a community coalition [speaking away from microphone]. They talk about the food banks and offering, you know, opportunities to families to get it. One of my questions was, okay, do all these places have [indiscernible] so we can get wheelchairs over the corner. They didn't bow. Okay. Are there any bus stops, what have you?

It was almost like, we'll get back to you, we'll get back to you.

It's almost like -- it's not just patients with developmental disability. What about VA? They're in a wheelchair because they're diabetic, what have you. So I think getting the communities to bring in the DD population.

Now there's a lot of wonderful community efforts for stress relief, what have you, for families to reach out.

So when I say, a couple of individuals in a congregate setting, there's DSP's or this individual has a grandma. But I think she would like to be there. It's more one on one. I think that engagement and getting communities involved with the DD population in whatever activities, the projects they have, not after the fact, but in the development process, I think that's really key.

Here in New York City, they have -- you're looking at hotels to accommodate the overflow of the hospitals or families that can't offer quarantine or isolation.

When you look at the checklist for hotels, there's 20 to 30 criteria that would pretty much rule out anybody from a congregate setting. So we were invited to the table after the fact.

So it's those things, proactive about getting more engaged, talking about what can we do.

I know Adriane and some people on the call, the high level education and training everybody and making everybody aware is all really wonderful and so important. But when you kind of drill down, here in New York City, [indiscernible] has been great, they have free testing and drive throughs, what have you.

But when you get down to it, looking kind of some more at the details and how the high level impacts the ground level. For example, the testing and nasal swabs have been a huge issue.

My patients who have severe autism, disabling behavioral disorders, I think two years ago, prior to COVID, that would be hard pressed to get a nasal swab.

So what training has that drive through technician had with that nasal swab? Well, what happens if you can't get it? Is it really adequate?

I struggle with it all the time getting information. Who is going to be trained and understand and what have you. But at the end of the day, the individual needs to have a nasal swab. Now what are you going to do?

Talking about vaccines, I'm fortunate, I work at the rose F. Kennedy center, surrounded by people that are caring, passionate, empathetic. So if we can't get a nasal swab, we'll try to calm them down, give them lunch. We know how to take care of these individuals.

I'm not worried about my individuals. I'm worried about individuals that see Dr. Smith down the road or Dr. Jones over here who may not have the patience or the time. You know? You're not going to get the nasal swab? I'll let it go.

Vaccines, I have patients that are scared to death to needles, having blood drawn, nothing. We'll do everything we can do de-escalate, desensitize, what have you.

I know that's my comfort level. I'm worried about everybody else. The vaccines are going to come out. Great, wonderful. Who's going to train the actual provider, the physicians to understand that somebody with autism is going to be scared to death of needles. What do you do at that point?

I am being going into detail. But when we talk about education and system and trainings, it has to go from top to bottom and really drill down to that one on one relationship. Who is going to be giving the vaccines? Add the end of the day, if that doctor or that nurse can't give that vaccine to that individual with down syndrome or autism, maybe a cooccurring condition of anxiety or bipolar disorder, you know, that individual has lost.

So what do I want to change is, again, proactive engagement, getting communities involved with our population, collaborating across congregate settings.

Whatever we do at a high level, make sure that at the ground level, who's on the ground, it really makes a difference.

So that's one. How are you creating problem solving and addressing challenges? I'll I think what was pretty impressive about our staff all over was how everybody stepped up. You always hear you have to do this, that. But it was amazing to me how many staff -- maybe figures, maybe a front desk staff answering the phone or nurses, what have you, they had these amazing IT skills.

They had amazing teaching abilities. So we had people that were maybe in a call center in a cubicle taking phone calls eight hours a day, but they were just so incredibly IT savvy, and they could train doctors on how to use telehealth. So creative problems, we shifted some of the responsibilities with our staff in terms of what their expertise and comfort levels were and utilizes them best we can, especially in emergency situations.

When COVID hit us, it took us a week to turn over and start providing our first telehealth service. And right now, I can tell you if it wasn't for some of the -- not back of the -- but staff that are more in the cubicles. If they didn't step up, I never would have figured out how to use Zoom, nothing. So I think that's how we're able to be creative and step up.

And also, we were able to see the leadership in those people. So I think that was really impressive.

Another thing that we also had to do, especially with the DD coalitions, unfortunately, a lot of these DP agencies don't have medical records, chief of medical officers. They have nurses spread out so **thin** that are well-meaning, but these nurses are looked at as the be all end all. They're overloaded.

So what we did was for the lack of a better term, we had virtual meetings that we targeted those agencies that did not have a [indiscernible] or nursing stuff that were overwhelmed and stressed out and a little bit lost.

We had these town hall meetings at the larger DD agencies in New York City. And it was more myself and couple other nurses and support staff and it was just an hour, hour and a half of question and answer, whatever we could, whatever we can glean from the CDC or updates at the time. We can maybe filter it better so it's not so much information overload for one poor nurse in ten different group homes in Staten Island. So I think that's -- I think that's the gist of what we're doing.

>> ADRIANE: Thank you, Vincent. Appreciate that. Yeah, and I want to just encourage those of you who are attending in the audience, feel free to start using the chat to throw out your questions for the panelists. We're going to be getting there in just a minute.

Just a couple of reflections from the hats that I wear and where I sit in addition to being at AUCD. I also am volunteering this year as the chair of the American public health association's public health education and health promotion section.

And couple of the priorities that I have are around making it a standard operating procedure to have accessibility communication whenever we're sending out health education information and making sure that that's also culturally competent.

And I wanted to mention that here as well because I think it speaks to the issues of intersectionality that are all of the panelists have brought up as well.

I just think there's an identity challenge right now, too, among public health practitioners, kind of feeling like, oh, well, this is the emergency manager's role. Am I really up to bat on this?

And I tell my colleagues, you're up. You're up to bat. It's -- you definitely feel free to use your tools and wear all the hats you wear. Get good information out there in ways that are accessible for everybody [chuckling] in the whole community.

So I wanted to share that. And that goes back to the points around being open to collaborate and think about connecting with folks that you maybe didn't connect with but you always could have, would have, should have. So that piece.

Before I turn it over to general Q&A from the audience is the issue around self-care. But more than self-care, being resilient. And feel like that's getting to be a cliché word these days. Be resilient, buoyance back.

This is hard work. I want to remind all of us here -- because I know we all contribute in different ways -- that it is good to take a break.

It is good to honor yourself as a human being when you need to take a water break or just get outside, get some fresh air, get some sunlight. Those are good things.

Take a few moments to do that throughout your day. That is critical so that you are here to do your good work after COVID is over. It will be over at some point. But it's something you just need to do to take care of yourself to set the limits, set the boundary so you can be here for the next time.

So with that said, let me see what questions the audience may have for us. Feel free to either use the chat.

I see a couple folks have just chimed in with comments here. If there's any questions, this is your time now to ask of the panelists. And you can either use the chat box -- or you do have the ability to take yourself off mute. Use your power wisely. If you're in a busy, noisy place, you don't need to take yourself off mute. But if you'd like to, you certainly can.

Looking at the chat, yeah, there's quite of few folks saying that they liked the ideas that were shared around communication and they may borrow some of them for other testing sites that they're facilitating.

And also, Linda mentioned here thinking about the other supports folks might need for communication services like augmentative and assistive technology. Good point, Linda.

I'm just checking out the chat, see if there's any other questions here.

And sue wrote in she worked with a lot of local public health and emergency management departments that don't get along. This is a local government conflict. Yes. Any sessions for getting EM and PH together with each other. I think that has Scott and Aaron's names all over it. Not to call you all out but to call you all out [chuckling].

>> SCOTT: I can tell you that when I was with Dallas county with emergency management, our county public health partners, there was a rough patch there. And I think what the issue was they always thought that EM was infringing into their particular areas and thought we were getting out of the lane.

The way we addressed that was through different trainings with exercises and letting them know that EM is not the lead in anyone. We're a support. Emergency management is a support and coordination.

We were able to use those particular trainings and exercise to show them that, hey, no, we're not here to take the lead or even tell you what to do.

You utilize us when you need a particular support resources, help, getting resources from other parts of government. It took a little bit of time. It's not just with county health and county EM or even local health or local EM. It could be with the fire department.

I can't tell you how many people think when you do exercises, EM is basically trying to show them up, show them they don't know basically what they're doing or they don't have a good plan. We were able to address that because we went with -- hey, your success is our success. Your failure is our failure. Again, we're here to support you. You tell us what you need.

You know, after -- it took six months. But after six months, I don't think -- we weren't going out and having drinks together, but there was a healthy work relationship.

>> AARON: To kind of talk about -- off of what Scott just said, man, I wish you were running our EM [chuckling]. I think, yeah, there's always been this conflict. It's not just public health and emergency management. It's -- there's relationship conflicts with any department and even in your own department that you're going to hit.

And I think building those relationships before any sort of emergency is huge.

All the people that we had great relationships with through exercises or developing different criteria or plans throughout the years, those are the ones that are really coming through for us, honestly, because we've already worked with them. They know how we work. They -- we don't have any issues going on. So that's -- that's always been, like, a good relationship thing.

With emergency, sometimes, you can kind of breakthrough some of those barriers because you're all getting no sleep. You're all going through the same thing together. And I think it's almost a make or break a relationship. So you really got to be careful because I've already seen through COVID when we're all agitated working 80, 90, 100 hours a week and mostly during March and April where some people are just at each other's throats.

But then other times, we're kind of laughing at midnight going, what the heck are we doing? [Chuckling]. We're all so tired.

And you start to create bonds that would have never been there if it wasn't for this emergency.

As far as, you know, emergency management, we're lucky to have a few good relationships there. But as Scott was saying, them supporting us, that is definitely the main role.

EM's are not really supposed to just take control of everything and run the whole operation, whereas people are definitely kinds of afraid of that.

In this situation, I think some of us would be, like, please, please, run something [chuckling]. Our emergency management was a little bit more on the side of, it's the public health crisis, so let them handle it.

It wasn't just you're the lead, but you're the lead and we're not in it at all [chuckling].

That's not helpful, either. So we've been trying to work with them a lot, and they have started to step up in certain areas.

And I think a lot of it was they don't understand how much we're doing. If we're not talking with them, if we're not really showing them how busy our lives are and what we really need and where we're failing, they honestly -- they'll just end their day at 4:00 and go about their way because we don't share an office or building with them.

Sole we asked them, can you come in on this meeting? It's not that we needed them at the meeting, but it is giving information. I happen not filtering thesis reports. I'm saying we're struggling here. We're 300 cases behind. We're getting further behind each day.

We hired 15 new people, but we still need 30 more employees and we can't seem to catch up. Just being honest.

And that goes back to when you're training and exercising those after action reports don't pull your punches because it's never going to help anybody to sit there and say, oh, we're doing great, doing great, you know.

No. Guess what? We're all struggling and it's not going perfectly.

Nobody can expect you to just take an extra 100 positive cases a day and you're hitting a thousand cases a day or something.

We were never set up for that. Nobody was.

So helping to bring other people in and understand that we're doing as much as we can and we're drowning and then they start to see that, and they realize, okay, well, how -- now they're kind of more willing, oh, how can we help? Add first, they were thinking we're trying to dump work on to them instead of we cannot handle this. It's getting dropped.

We're not trying to drop work on you. We're trying to just stay above water. I think bringing them in was huge and just telling them what our situation was on a day-to-day basis, they could see how we're trying to, you know, meet those gaps and then I think it also is good to obviously acknowledge them when they -- for us, they set up a call center because we were -- our average wait time hit over two hours just to get a person on the phone through our call center.

Because we were having a couple thousand calls a day. So they actually set up a little call center at their public safety training facility, and they reduced our wait time down to about 20, 30 minutes.

And in the next situation reports, I was praising them for that, and people were actually able to have a night to see their family for once instead of trying to take calls until 9:00 or 10:00. That, I think, really helped the relationship and helped them understand that they're super appreciated.

And we need their help to support this mission. We can't do it on our own. So I think, again, kind of to that point, yes, there's lots of conflicts in any department, and I think just really trying to include them, give them the no nonsense where we're at.

We're trying to -- not trying to dump work on you. But we need your help. Can you help us? We'll get your back if you have our back. We'll help you out if you ever need it. That's my two cents on that subject.

>> ADRIANE: Thank you both, Scott and Aaron. Any other questions from the group? I have another one generally for the panelists over all, and it relates to trust.

Right now, it is still information overload for many. How do you deal with some of the public's mistrust for information that you are giving? And what are some work arounds? Thoughts or strategies on that?

>> SCOTT: Well, I can tell you how we deal with it.

We keep saying communication with communication is so key. We talk about making sure we provide good information quickly. Sometimes we're not the best at doing that.

And then if we provide a particular message out that's wrong, we really don't like to admit we made a mistake. It's okay to admit we made a mistake.

That's where the trust will be. Providing consistent, reliable information. We have joint information centers that hardly ever get used. We're the worst at following our own practices sometimes. We got the plans in place and we shoot from the hip when the real deal hits [chuckling]. I don't get it.

But if you're consistent with the information you're providing, and sometimes admitting, sometimes you don't know, there's lots of conflicting information out there.

If you don't know, provide recourses out there. We try to load our page up from everything from mortgage assistance -- this particular disaster has caused so many things besides the illness. People unemployed, not enough money for rent, food, what have you, and be able to anticipate these particular needs ahead of time and providing that information. Again, in multiple places that they can get to it, I think it helps establish that hey, when times are tough, they're going to rely on the government.

Because if we look like we don't know what we're doing, we're in trouble. If we don't look like we know, the trust is going to be completely lost.

>> ILKA: The other piece, I appreciate what Scott said. This is where really those relationships -- if you talk specifically about disasters and people with disabilities, this is where

we would hope to have those relationship with emergency management, with public health, with our local responders, give us the information because sometimes what we experience is there are certain groups that really don't trust the government at all, and it doesn't matter who you are, what you do.

It is just a general mistrust, and they're just going to, you know, pull one over on us or they want to give us some stuff that's poisoned for our body or whatever it is.

I mean, there's lots of that stuff out there, too. And I think we try to then channel it also to our trust partners.

So maybe we have a specific group of African American families that have kids with autism who really -- they need to hear certain information through their trusted, you know, community health worker who can then make a difference.

Or you know, through the other moms who are, like, hey, it's a good thing to get vaccinated or, you know, whatever it is.

So I think making use of relationships with people who can get that information out in a way that people trust it or that people can understand it -- I mean, sometimes you have information that we really need to adjust and make more accessible because it isn't accessible.

So I think those partnerships, I think, would be really appreciated by the centers for independent living, I think they're great partners in something like that. The UCCEDD or other disabilities organizations to get that information out and to communicate that.

>> VINCENT: Here in New York -- maybe it's a question for Aaron or Scott -- do you connect with the disability agencies? Here's they're called office for people with developmental disabilities. What I find here is that families will come to us to ask question about health care, obviously.

When we're trying to give information, families, patients, group homes, staffer, what have you, we'll obviously site the resource. Based on the DOH website, CDC website, so forth.

What I've seen here in New York state is they'll go to the OPDWH website will -- I'm learning a lot myself. With emergency management, public health, I was -- health and hospital corporations, what have you. There's really no drama here in New York City whatsoever. I was just wondering do you communicate with agencies that have one location? Because here in New York, the OPWD has a great website, so does DOH. So does office of mental health.

>> AARON: We definitely communicate with those groups a lot. It's all about transparency. With the public, there's going to be some questions, like, are these going to be tracking devices in the injections? No, we're not going to address those ridiculous questions, but I'm lucky our Dr. Mendoza is our commissioner of public health and he's 100 percent just all about being completely transparent whenever he does a briefing.

He has us even kind of asking volunteers to do a rumor mill thing and if we hear certain rumors that keep getting speed and it's something that need to be addressed, he puts it out.

We have kind of Scott's case. We have certain things where we messed up the numbers on one thing or here's why there's a difference between New York numbers versus the county or regional numbers. Mendoza will put it out there and say, you know, there was an error on the

reporting for last -- yesterday or last week, and this is why it happens. This is how we corrected it, and this is the reason behind it.

And you will get so many people pissed off about that, but it doesn't matter because people are seeing that if you're willing to make those kind of -- it's an uncomfortable situation to say, yeah, we screwed this up and here's the real information on it. But I think people then can trust your information more as you go forward because they're, like, well, if it was -- if they didn't know, they'd say it.

And Dr. Mendoza said that multiple times where he's saying we don't know this right yet. We're working on it.

We're trying to see the correlation, but we don't see it right now.

We have -- since April, March or April, we had biweekly meetings with all the colleges and schools' long term care groups and coalitions that we try to meet and try to figure out different cases and different scenarios.

So it's a lot about not just putting out the wide spread media stuff but also saying, okay, OPWDD, this is what we just got passed down from, you know, CDC saying this New York City state, DOH was saying this. This was our take on it, and clinical standpoint.

What are you guys facing? How can we help? What do you need from us? We just keep those panels open.

And sometimes, the meeting might be quick in saying, yup, nothing's changed. Everybody's busy. Have a nice day.

But then sometimes, they bring up really important discussion topics and we take it back to our team, try to figure out what our stance is on it, and what the clinicians say and then go back to them.

It's all about following through and following up. It's a lot [chuckling]. And like I said before, our hotline had over two-hour wait at one point. But that's also because we weren't dropping calls. We weren't sitting there, going, okay, well, these ones are really ridiculous questions and we're not going to answer them.

Everyone will get a call back. Even if it's two days later, they will get an answer to their question and we'll have somebody who researches, find the reference, is it on OPWDD's website, New York's website? How can I take a picture of that, email it to the person or get them on the phone, and stay with them to guide them through the resource.

Our calls sometimes take longer because of that, but we're feeling for the people that are getting passed around where they call five different places and they get the run around and we don't want that.

So we're trying to do that run around for them, find the information, connect them to the direct source. That's what we're trying to do.

And there's lots of resources out there. Don't just sit there and try to reinvent the wheel.

If there's an issue at an nursing home guidance, we're going to talk to that community. We're going to talk to OPWDD. We have to go to those subject matter experts because they're going to know a lot more than we're going to know on that subject.

>> SCOTT: Aaron, you're so right when talking about the follow through. One of the agencies I was trying to engage with an action committee, and it was hard. A lot of the disability groups just didn't trust county government. They've been over promised and always under delivered. And it impacts. You talk about having to jump some hurdles to establish that trust.

That follow through is absolutely key. Great, great, great piece.

>> ADRIANE: Yeah. Thank you for that. Aaron, did you want to add anything else?

>> AARON: One thing we did notice in a lot of our underserved communities, they didn't like the direction from -- or a testing site that was -- people that were white or from males or something like that. We worked with the black nurses' association.

We've worked on trying to figure out if you're not trusting this group, how -- how can we provide you either information or a liaison that you do trust. And we've kind of reached out to some kind of community leaders, even, and said, okay, well, can we kind of talk with you? And you relay that message and if you have concerns from your community or group, then you come to us with those, and we'll sit down and try to hash those out and figure out how we can overcome that.

It's, again, a lot of time. But it's trying to reach those populations and figure out, well, why aren't you -- why don't you trust the system?

And you find out that some of these groups that are maybe from different nations, some of them -- a lot of them, actually we were dealing with were refugees and they saw their government before really didn't help them out and hurt them.

And some people when they went to medical facilities, they never came out, so they were really terrified that this was going to be a repeat of that. So trying to understand that cultural aspect, getting -- and getting the buy in from the community leader or that religious leader really helped us to kind of make a breakthrough in those communities that were actually clusters that really started to spread COVID a lot because they wouldn't go -- they wouldn't self-identify.

They were traveling, car pooling. They didn't wear masks when taking breaks. They wouldn't listen to our guidance. But when we broke through to their leadership, then they listened to that leadership and really started to listen, which was great.

>> ADRIANE: Thanks for that wrap-up, Aaron. And thank you for everyone's active participation today.

We are at time, so I'm going to wrap us up. I think those last pieces around building understanding and trust are really critical to support our ongoing work for sure.

Want to just let you know that we always want to stay connected with you. Really just to hold each other up in this work, let you know you're not alone.

There are two different ways we can keep in touch beyond the AUCD all year one, one through our health and disability special interest group.

We specifically focus on health promotion, areas around health care transition. And so I have the link there. You'll also get copies of the slides as well so you don't have to frantically write that down. We'll share that with you.

The other group I'd invite you to join if you're not part of it, is our emergency preparedness special interest group. That is a great way to stay in touch with each other throughout the year.

Thank you very much for your time and attention. Hope to see you at all pre-conferences and during the main AUCD conference.

Best, and be well. Thank you all so much.

[End of event].