

AUCD
Disability in Public Health COVID-19 Town Hall-(Zoom)
3:00-4:00 pm
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>> Good afternoon, good morning, welcome, everyone, I'm Adriane Griffin and want to welcome you to our disability and public health, COVID-19 Town Hall. Today, we'll have about an hour. The first thing we're going to do is hear some mini presentations from folks throughout the network, then we'll move into some breakout sessions. So... speakers that you'll hear from today will focus on programs that have been helpful, resources that have been helpful, for the disability community and the response to COVID-19. I do want to let everyone know that you are muted, you'll be unmuted once you're moved into the breakout rooms. For those who haven't let us know what breakout room you'd like, please do take the survey. We're going to pop the link to that into the chat box for you and... today's session is going to be recorded and as always, cataloged on the AUCD webinar library. And at the end, there'll be an evaluation survey. Let us know your feedback.

For the Town Hall today, we're hearing from speakers across the network who will share some programs and resources that they have found to be very helpful to them in the response to COVID-19. They're going to share mini presentations. First we'll hear from Ilka Riddle. She's with UCCEDD there. Next, we'll hear from Laura Stough with Texas A&M. Then we'll hear from Bryan Russell with Florida Department of Health. Then Julianne Mills. And Tara Lutz.

AUCD has a motto that public health, we work together around advancing policies and practices, education and social and economic well-being of everyone in the disability community as well as their families and communities. We want to giving you a resource, public health is for everyone toolkit. Phetoolkit.org. Please let us know what is working well for you, so we can add that to the toolkit and you can make suggestions as well at phetoolkit.org.

I'd like to let you know the agenda and game plan for today. We're going to hear from our presenters that will share mini presentations. They'll have about two minutes to share highlights, programs, resources that have been effective for

them and then we'll put you into breakout sessions so we can really hear from you. And this is just a reminder, if you haven't yet completed the survey to let us know what breakout room you'd like to be in, do that now. There's a link in the chat to follow that survey. There'll be four groups to choose from. Group one is around disability awareness, stigma that we've been dealing with and social norms. Group two is around disability inclusion and public health efforts and really, how do we get the public health including disability on a regular basis, not as an afterthought.

Group three is around medical and Health Care advocacy and thoughts and strategies on that. Group four is around disability inclusion and emergency management. Let us know where you'd like to be and take that survey and we'll come back together in a large group to do high-level reportouts so we can share from what each group is learning.

So... if you have a couple that you're interested in, know you'll get to hear the feedback from those groups as well. And then we will wrap up.

So... without further adieu, I'd like to pass the virtual stage, microphone over to Dr. Ilka Riddle. Ilka?

>> Ilka: Thank you so much, Adriane. I'm going to go right into my presentation since time is of the essence here. So... I wanted to share with all of you, some of the COVID-19 responses from our UCEDDs and hopefully you find those helpful to you. If you could move to the next slide.

All right... I'd like to start with training. I organized them by the four core functions of our UCEDD. The first is training, once we had to go back home for the stay at home order, we provided our leadership education and neurodevelopmental and other disabilities trainings for our trainees and students in the developmental disabilities certificate class, as online instruction. Probably like most of you.

We converted our in-person training sessions that we had already planned and developed new training sessions for virtual webinars based on the feedback that we received from self-advocates and family members about what they felt was needed and it was interesting, kind of like the progression over the last couple months, in terms of how needs changed from like, immediately I need to know, what do I need to do next? To protect my loved one, to more like, how do we go back out into the community and be safe?

We also provided real life examples and models of how some of the families that either are connected to our UCEDD or work in our UCEDD, adjusted their life to the new normal because... you wanted to demonstrate to families what they can do to create a good life for themselves and their children or adults with disabilities at home.

We also collaborated with our Department of Developmental and Behavioral Pediatrics where we are housed on video learning modules for learning modules for families to give tips on behavior, how to exercise, how to establish routines, address behaviors, things like that. And we collaborated with AUCD on national four-part webinar series regarding people with disabilities and how we can be all prepared and work with and during the times of COVID-19. Next slide, please?

We also had community services collaborations with AUCD, the American Psychological Association and our Center for Dignity as well as state and regional collaborations, so... that we could address regional and local issues as well. Next slide, please?

We did a lot of work around research and policy, so... we have a new Center for Dignity in Health Care. We developed a fact sheet for families and how they can advocate for themselves, as well as collaborating with our DD Network Partners on how to address the issues of hospital visitation policies and medical rationing and then we also worked on a publication regarding raising awareness of disabled lives and Health Care. Next slide.

Then, like most UCEDDs, we were active in dissemination and still are. Regarding some of the issues we've seen with COVID-19 and developed a specific COVID-19 section on our website, as well as get information out via Facebook, Listserv, send out action alerts and then still continue to provide support for families, one-on-one. Next slide.

And finally, I just wanted to share our resources that you will have in this presentation and after the presentation, where you can actually look up the things I just mentioned and with that, I'll give it back to Adriane.

>> Thanks, I'm going to have the slide forwarded and pass it off to Laura.

>> Hello, everyone, this is Laura Stough. I lead Project REDD at Texas A&M university. In most states, emergency management is working hand-in-hand with public health in response to COVID-19. Our SIG is more important than ever, I'd love for you to join us. Look on the AUCD website under the issues tab to join the Listserv. I think we have capacity and connections to amplify the response to this pandemic, so... I'm just going to summarize some recent examples of how we, at the center, are responding.

First... we're connecting the disability community with emergency management and public health. Right now, we're participating in one of the COVID-19 working groups for public health and social sciences research. Sponsored by the Natural Hazard Center at University of Colorado through funding, through NSF. Together, with 14 scholars from nine universities and centers, our work group is a think tank on emerging research and issues

regarding COVID-19 and disabilities. You can see other work groups, including some on mental health, that you see on the slide.

Another way we're connecting the disability community with emergency management is through our Disability Task Force on Emergency Management. What you see is a link to our effective communications toolkit, which is directed at emergency management and public health information professionals on how to modify communications so they're inclusive of people with disabilities and you can download a copy of that communication toolkit.

Second... we continue to provide resources and information on COVID-19 to the disability community. That link is to our resource list, which includes national and international resources. You're welcome to copy any of those resources for use on your own centers resource pages, just a note of acknowledgement is all we ask.

Next slide. Then... third, we continue to develop tools, services and supports for people with disabilities that, personally, that you see there, is to a list of disability resources that we have on an online guide, on our website and then... that second link that you see there is a handout that we developed to craft guidelines for hygiene and social distancing, based on the CDC guidelines. That are modified for people with disabilities. We are distributing that handout to our state Department of Health Services and also to public health authorities in local districts throughout the state. You're also welcome to download that and to distribute that to your own local health authorities.

Next, we are protecting the continuity of our organization by crafting guidelines for use within our own office. The bottom line is this. COVID-19 poses a particular threat to individuals with developmental disabilities that have underlying medical conditions. And... recent reports suggest that the fatality rate for people with disabilities and COVID-19 is two to five times higher than in the general population.

As such... our center is following CDC's Phase I dating criteria of having downward trajectory or near zero incidence of documented cases over a 14-day period before we open more offices. We think this is a way to help protect the community that we are serving.

Finally... as I said before, our center, at our center, we really support and encourage each other to take precautions, so that we, ourselves, remain healthy. Everyone on this call is a valued asset to the disability community and we all have work that serves the disability community. As such, we need to take precautions to protect our own healths so we can continue to do that work. Within our centers and across the network.

So... I'm looking forward to meeting with some of you later today in emergency management Town Hall. Thank you.

>> Thank you, Laura. Next, we're supposed to hear from Bryan Russell, but I believe he may have been called away, Bryan, if you're on, please take the microphone... and I'll do a quick scan to see if you're here. This is live TV, folks, Bryan is deployed, right now, checking ADA accessibility at COVID testing sites, so... we will not hear from Bryan at the moment. Anna, if you could forward the slides and I'll ask the Julianne to step up and share. Julianne, I'll let the virtual mic go over to you, please, thanks.

>> Julianne: Thank you for having me today. I'm a program manager at Move United. I'm participating in today's Town Hall on behalf of Move United to share with you all the way we are adapting the work that we do, so... we can help meet the needs of people with disabilities during the pandemic.

Next slide. And... actually... we used to be Disabled Sports USA. You may know us by our former name. In the midst of the pandemic, we had been in the process of going through a merger between Disabled Sports USA and Adaptive Sports USA and are pleased to announce our new name that seems fitting in these circumstances to come together to do this great work in support of promoting physical activity for people with disabilities. Next slide.

So... now, we've formed to become one of the nation's largest multisport, multidisability organizations, offering community-based sport recreation to youth and adults with disabilities. We have a network, currently of 158 network organizations and growing across 43 states. Here you can see where our member organizations are located around the country.

You can find your local organization or learn more about membership by going to our website moveunitedsport.org/membership.

Next slide. And... a new program that has come out of the pandemic is this adapt at home initiative where we are working to offer virtual fitness and partnership with our member objections and other providers free virtual activities that people can do fitness at home.

So... since April 1st, our virtual events calendar has curated and featured over 500 live and on demand events and over 30 sports fitness and wellness activities. Strength and conditioning, cycling and Yoga have proven to be our most-popular offerings so far. And we're excited to see how people continue to innovate and bring communities together, all in the interest of staying well and fit as best we can during this time of social isolation.

Next slide. And here, I've just highlighted a couple areas on our website that may be of particular interest for resources and support, we're working on providing brands and guidance on reopening for our member organizations.

We're also curating a library of news resources and other events in education to assist providers.

So... you can learn more about different types of adaptive sports and equipment. And... also, you can seek out free professional development opportunities through our online courses, webinars, and recently, we hosted our annual leadership conference online, which was able to serve about 2,000 people around the world.

So... that was a pretty incredible jump from what we usually see, 1 to 200 people, mostly just the U.S. and Canada. So... definitely check out those resources so you can find what you or your community may need to help stay active and fit during this time. Next slide.

Here... I just included my contact information, so... if you have any particular questions or... need any assistance navigating our website, I know it's this evolving, kind of massive resources, so... definitely feel free to reach out to me and I'll help point you in the right direction and get you linked up.

>> Next up, we'll hear from Dr. Tara Lutz from the UCEDD at UConn.
Tara?

>> Tara: Thank you, we can go into the next slide, please. Hello from the CT UCEDD and CT LEND program. I have the opportunity to spotlight our resource today. Thanks to AUCD and the National Center on Disability and Public Health for this Town Hall. I will be showcasing our tip sheets, which are quick summaries for specific audiences that use plain language. Next slide, please?

Early on in the COVID-19 crisis, our center recognized the need to help the community sort through all the information available to them. As shown on this slide, our center organized COVID-19 resources by audience or topic. Under the leadership of our director, Dr. MaryBeth Bruder, our center has expertise in early childhood among other topics. ECPC is directed by Dr. Bruder is the first option. ECPC resources are organized by audience. Part C and B/619, IHE faculty and families. Here's a tip sheet titled enhancing family-provider partnerships during COVID-19. It includes questions that have been asked by families and answers about remote service delivery. For example... what if my only option to continue my child's intervention services is through remote home visits and I'm not sure I want to do this? Or... what if I don't want a remote visit being recorded?

Other examples of tip sheets for families include receiving remote early intervention services, and how to prepare for remote early intervention visits. Both are available in English and Spanish. Next slide, please. For more information, please contact Dr. MaryBeth Bruder at her e-mail

Bruder@UCHC.edu and check out our websites. The UConn UCEDD and early childhood personnel center. Thank you.

>> Adriane: Thank you so much, Tara, we really appreciate that. Next, we'll move forward to our breakouts. We have four options for you. If you have not yet done the survey, please do so now. We know where to place you for the breakout. Group one will be around disability awareness, stigma and social norms. Group two around disability inclusion and public health efforts. Group three will be around medical and Health Care advocacy and group four will be around emergency management and disability inclusion. We'll have breakouts for about 20 minutes and... then we will come back together and have a sharing out, so... when you get into your groups, we will need volunteers for you to serve as note-taker, as well as a volunteer to serve as a reporter on the group breakouts.

That was all I have. So... Anna, I'll let you do your magic to get us into these groups.

>> Hello, everyone, looks like folks are coming back to the main room. I must say, I'm enjoying everyone's backgrounds. Some people have beautiful backgrounds. All right... looks like we have majority of folks back here. I want to be mindful of time, because... we want to have our reportouts with our captioner. I'm going to call on the first group. Valance, you are up. If you're with us, please take the microphone and share the highlights of group one.

>> Valance: From my point of view on the group topic was mostly just about different ways we can could reach out to our loved ones in the disability community and different ways we could do things to make them aware of COVID-19 and how it's affecting them and all of us, actually. It was good to hear the different feedback from everybody, different things we could do or different ways to approach this whole COVID thing with our line of work. Or with the type of people we surround ourselves with. That's mostly what I got out of it, us just ping-ponging off each other with our different views and stuff like that, mostly towards the same goal of always helping these ones in this field. During these strange times that we're in. And it was really nice to hear everybody's feedback. I'm sorry, typhoid step out too, for a second, I didn't catch everything, but that was mostly the gist of it, I think, correct me if I'm wrong, though.

>> Adriane: The only other thing I'd add is that we talked about the whole family, as well as caregivers, as well as other special educators or para educators being integral in giving individuals with disabilities getting support right now. One in four Americans have a disability. Those were other highlights from me too. We'll also have notes we share out from everyone too. Thank you to our scribes and reporters in advance. Thank you for group one. Want to keep us on time -- group two -- if you're a reporter, take the microphone.

>> Emily: Hi, everyone. From what we talked about in group two, it's basically making sure that everyone who is getting access to health -- I mean, to public health needs in the disability community who are actual self-advocates or advocates, have their voices heard and... also... it's been a challenge for people in rural areas to get the necessary virtual means met, like... people who are in rural states like Vermont, for instance... there's been resources and ideas shared about how to improve that, like... the respectability toolkit. Some people in the network like Cairo, who are developing training for people in public health professions to include people with disabilities and... just the changes of information. Just being a struggle. On a daily basis and... Jordan, if I missed anything or anybody else, please feel free to fill in the gaps.

>> Appreciate that. Good to hear your voice and see your lovely picture there. All right... group 3. The reporter could please take the microphone.

>> This is Teresa. I was part of group three. We had a lot of rich conversation -- it was wonderful to be part of that group. We started with a question of how can Health Care providers better-serve individuals with disabilities. I appreciated where we started in that this is not a just COVID-19 issue. This is an ongoing issue and that hopefully with emphasis on, are we meeting accessibility? Are we serving the individual as an individual person? Not just a disability category, that those pieces, as they're being considered now, could be maintained in the future. A good conversation on how are we making sure there's regular training for the professionals, for the Health Care work years what is accessibility? And... that being very broad in that it being the physical and sensory and the language and intellectual. When we're looking at cultural competencies for medical training, we tend to add in diversity training and we specifically need to be looking at disability training within that diversity training as well. I thought that was a beautiful point to be making and a consistent one across several of the members of the group.

We moved to a conversation, then, on telemedicine and did that make things more accessible? Did that provide opportunities from an individual perspective? Yes... they had a recent experience they liked and valued that opportunity to access telemedicine and that they found it beneficial to be able to receive that care from a place that they were comfortable. I thought that was a valuable statement there. But that, you know... in that ability to have telemedicine, is there a need for access to technology? We start talking about rural settings. Is there a barrier created that we don't have access for everyone. Are services available for everyone? We did conversation around, if we expanded networks and cross state lines, what policies need to be in place to look at licensing and insurance. Let's see... and the last piece to throw in, we need to be working on systems levels and primary prevention. Orienting Health

Care providers to mitigate risk and discharge to the community is at a higher level than workforce development and training.

>> That's the challenge. Great. Well-summarized, thank you so much.

>> There was a lot of great minds in one room. Good people.

>> Awesome, thank you for being the reporter. Appreciate you. Last up, reporter, can you take the microphone?

>> This is Linda -- we didn't really quite follow the scripting that was there. I jumped in and said, not only do we have COVID issues going on, but... now, as of yesterday, hurricane season for much of the country has begun. There's a storm in the gulf as we speak. And the issues the overlay of COVID has for that. There was a discussion on what are we going to do for emergency response? Which is close up to the people when doing an emergency response, during an emergency with COVID issues. The volunteerism of feeding and supply distribution during emergencies as well as sheltering. If you cannot shelter at home, what are we going to be doing? Both FEMA and Red Cross are definitely stepping up and speaking into different kinds of sheltering than what we looked at before with the empty hotel rooms maybe being used. Empty university dormitories, empty public school classrooms versus the large auditoriums. So... some things that if you are in those areas or tornado alley or... where there's fires prone in your area, all of those issues coming into play and thinking things through on that. Tammy said they received one of the FEMA grants on disaster crisis counseling. It can overlay if there's an emergency event as well. It'll be a totally virtual outreach focusing on the aging population and IDD population and their use of the grant moneys for this virtual support and outreach and information and referral. I'm hoping they get lessons learned on ways to utilize that beyond COVID times. They're partnering with the mental health agency of their state for bringing those services together. That led to Paige with our Florida Centers for Independent Living. Our state headquarters for CIL and talking about what Florida's been doing. And there's been great leveraging of resources and conversation on a weekly basis. Bryan Russell would have been telling this. Paige did a great job encapsulated weekly calls across multiple agencies and organizations that touched the lives of people with disabilities. Partnering with new people in new ways that haven't happened before.

But... the response, it creates some one-stop shop services that get out to those folks who utilize paratransit services and aren't able to go take care of grocery shopping and food prep. It's a silver lining. Now those things will be in place if a new emergency hits at some point because those connection points have been made. The wrap-up by our leader, we're figuring out new ways to do things and it might not be best practice, but what we can do to come together creatively to provide those services and supports. That's it in a nutshell.

>> Wonderful, thank you, Linda. I appreciate all of you taking the virtual stage to share what each group spoke about in more detail. That was really terrific.

I want to move us along and wrap us up. Thank you for joining us today. We'll just... close by saying you know... this Town Hall was a progression that followed up on the series of webinars that we'd done around COVID-19 and the disability community. We want to take the lessons that we're learning and make the systems better and... build better and new ways to be smart about our public health infrastructure. We believe public health really is for everyone. That includes the one in four Americans with a disability.

So... with that said, I do want to let you know, we will be taking the notes from each of these breakout groups and incorporating them into some feedback. We have the ability to give to some of our national partners in the emergency response and next phases, what this looks like so we can be better, more-resilient and inclusive of people with disabilities. So... just want to say thank you all, so much for your ability to be with us today for this hour and sharing robust, deep comments for this is really meaningful. We appreciate it. We want to thank you for joining and... please take a moment to take the evaluation that will pop up when you leave. Thank you all so much, take good care. Be well.

[Call concluded at 3:59 p.m. ET].

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