>>Philip Kahn-Pauli

Good afternoon and welcome to the RespectAbility webinar for today. My name is Philip Kahn-Pauli. I appreciate you taking the chance to join us this afternoon. We're gonna be talking about Covid-19, the coronavirus - how it's impacting the disability community and taking care of ourselves and our mental health in this very trying and uncertain time. So I'm obviously a - my title is that I am the Policy and Practices Director for RespectAbility. Our mission is fighting stigmas and advancing opportunities and I will fully say that I am NOT a public health expert, I don't typically work on health policy and I'm certainly not a viral epidemiologist pandemist - I played the board game pandemic a couple times and that is the sum total of my expertise so I will be very cognizant of what I don't know, but I do know that we have a vested interest together in getting accurate information out to the disability community, to our friends out in the world who are being impacted by this very serious situation. As my colleague Eric was just saying our team in Los Angeles is gonna have to find a new event space because it turns out that the place where they were going to have an event tomorrow actually is being shut down because of the virus. We are all dealing and adapting as best we can, so we've got some wonderful people joining us today, so you've got me and I work on employment.

Joining us from Ernst & Young is Lori Golden. She is a thought leader in the disability inclusion and advocacy - disability inclusion in employment space. She's led some very, really innovative work around mental health in the workplace, managing stress and she's gonna be bringing in that expertise to us today and because at the end of the day, this is a situation which is very good for spiking one's anxiety and stress levels but really limiting - it's challenging to find what you can concretely work on or do to take care of yourself. Also joining us is Donna Meltzer from the National Association of Councils on Developmental Disabilities. She is the CEO over there. She is a longtime leader in the disability space and she has members in every state and territory. Getting good information out there is part and parcel of her job. I'm also very excited that the folks from the - two people from the Partnership for Inclusive Disaster Strategies, and I apologize if I'm gonna mess up your names but German Parodi and Shaylin... how do you say your last name, Shaylin? Sluzalis. Sluzalis. Both of them are actually- they're disability rights leaders, they're advocates with significant subject matter expertise in the area of disaster relief, inclusive disaster planning, emergency preparedness for people with disabilities - and thank you both of you for joining us. They are the real experts in this space. They have flown to Puerto Rico to deal with Hurricane Maria, they have been intimately involved in the development of the REAADI Act which I hope we can talk about a little bit, they come out of the Independent Living movement, they are really the experts in this and I will be deferring to their expertise and talking about their national call to action that they've laid out on Covid and the disability community. But first up, I want to talk to Donna and bring you up first.

Here is a quick map of - this is a day old or a couple days old but it shows that in many different states in the country have been impacted by coronavirus. We just last night, I heard of the first case in Prince George's County, which is in the DC Metro area and there's just a lot of fear and a lot of panicked toilet paper buying. But, you know, Donna I want to ask you first what have you been hearing from HHS, from - what information you've been putting out to your membership, kind of, where are your members who represent the IED community, just where are we, what is going on and what do people need to know from your perspective?

>>Donna Meltzer

Thank you so much, Philip, for laying that out and asking some really great questions. I appreciate that you also talked about - you mentioned the word panic, and part of this webinar is to really give you guys some very real information, important information, because I think that when we talk about how to bring down that stress level, a lot of it is when you know information, when you feel secure in the knowledge that you have, some of that stress automatically goes away. There really is no need to panic. There's need to be informed, there's need to take some very important steps in keeping yourself healthy and well, as well as taking care of those who are around you. If you are with people who need some extra support and extra information sharing. So again no need to panic I know my neighbor told me the other night she had walked into Costco and people were taking every bottle of water off the shelves and I looked at her and I said, "You know last I heard nobody is shutting off my power - you know, my electricity, my gas line, my refrigerator still works and it dispenses water, and my stove and my oven work and there's plenty of food and this is not Armageddon." So I think we all need to really start by taking that deep breath and remembering that this is not a panic situation. This is a situation about knowing information and keeping yourselves healthy. So here at NACD in our national offices in Washington DC, we have been in multiple meetings over the last two weeks with our federal partners and that includes people at the Administration for Community Living which is under the Department of Health and Human Services. Also the Assistant Secretary's Office of Preparedness and Response, also part of HHS. We've been talking regularly with the CDC and particularly from the Office on Disability and the National Center on Birth Defects and Developmental Disabilities to be sure that we are, number one understanding the scope of what this disease is and, when you can understand that better than you know what protocols to take. And really what the CDC has been very clear and talking to us about is that, this disease Covid-19 is very very similar to the flu. But there are some important things that you need to think about, both in terms of what do you do and what size should you look for. So for example we all know that particularly in the winter months, flu does run rampant, and we know that one of the best ways to manage not getting the flu is to get a vaccine, but we don't have a vaccine, at least not yet, for coronavirus, but the other most important thing that I'm sure you've all been hearing plenty of, because it's real, is wash your hands. And what we're hearing from the experts is you need to wash your hands for at least 20 seconds, soap and water - does not matter what kind of soap, it doesn't even matter if it's hot water versus cold water. It's the real act of scrubbing and getting those germs off of your hands. So we need to remember to wash frequently, to use hand sanitizer if we need to because we either can't wash at that moment or we want a little bit of extra protection. I've taken the caring just a small package of antiseptic wipes with me so that if I'm around a surface that I'm not familiar with or don't know who's touched it, I might want to wipe down say a seat in a Metro train or on the bus or wherever you might be or when you walk into the supermarket they're handing out wipes so you can wipe the handle of your cart or your basket that you pick up in the supermarket. So really those very very simple things are what you do need to follow and remember to do.

And staying at home is just fine - most big meetings have been canceled. I know from our organization it broke our heart but every year at this time we are a co-sponsor along with a number of other national disability organizations of a big conference that brings together about a thousand individuals to come to Washington for two days of learning and discussing policy issues and then have a day up on the Hill, and we have to cancel it. There's just no question about it. Some people were concerned about the risk of how much money you lose when you have to cancel hotel contracts and food and and everything else but honestly, our thought was the risk of losing money is nowhere close to the risk that people might be put in, that could make them sick or even cause death. That was just - never a question in our minds. So you really have to think about how do you keep yourself safe. We're hearing a lot about the need to stay away from large meetings or tight spaces where people are very close together. So I think that from my perspective, from what I'm hearing from the experts is that, it's okay to be in small group offices or meetings, or check-in on your loved ones or others in your community, but you don't want to necessarily be in big groups or places where you're very close, like that literally spitting distance, you don't want to be in a situation where somebody's - what comes out of somebody else's mouth could actually reach you. So you want to, no shaking hands - we're all getting into that little either fist bump or elbow bump or just a simple greeting of "Hi, how are you? It's so nice to see you," but we don't need to be touchy-feely during these times.

I think for us again at our National Association, we're trying to push out some really good basic information - we're working with the CDC in terms of getting some materials that are in plain language, in particular for people who have intellectual disabilities. Some words are just not part of the everyday lexicon and so we've asked CDC to put protocols - and I know NIH was coming out with something earlier today as well, it just kind of talked about a couple of really important things that you need to keep in mind and that you need to do, like the hand-washing like not going out in public: if you think you're sick do not go walking into your local drugstore to pick up medication, do not go to the MinuteClinic. If you think that you're sick, please call your doctor who knows you best, talk about your symptoms and then let your doctor recommend whether or not you should come into the doctor's office or if you need to go to the emergency room. One of the things that the medical professionals at the CDC also shared is kind of the trajectory like, if you've ever had a cold, and who amongst us has not had a cold or the flu, you kind of know that you start getting symptoms and somewhere around day five or six you start to feel better right. The typical cold lasts anywhere from seven to ten days, but with coronavirus it's around that fifth or sixth day that you actually start feeling worse, and if you start feeling something in your chest that is pressing on your chest that it's making it more difficult to breathe, that is when you really want to call your doctor because you might have been exposed and that is something that better to get tested and be sure, than to be walking around and being a carrier of this disease.

I think this is an important point as well if you are somebody who knows people in your community who are people with disabilities who are living independently - if they don't have somebody who's checking in on them regularly, making sure that they are healthy, that they know what the protocol is, please try to get to them check in with people even if it's just by phone or if you communicate by cell phone to give somebody a text just to say "Hey I'm just worrying about you is everything okay? If you start to feel sick or you're afraid or you don't know what to do, call me, let me know I'm here to help," and through our Councils on Developmental Disabilities, we are trying to get all of that information out to folks. Another point that I'd like to make is that in our disability world a lot of people are employed as direct support professionals - DSPs. They're often on the front lines - they are the people who are supporting people with disabilities every day... in close circumstances going into people's homes, helping people - doing everything from taking medication to sometimes needing to support somebody getting out of bed, getting bathed, getting dressed toileting, etc., so very touchy-feely, very hands-on. So if you are a person who has a DSP, make sure you're having the conversations with them to talk about what might be a little bit different right now, and they should be talking with you about their protocols. The DSPs are getting a lot of education this week from some of their national organizations - the National Alliance for Direct Support Professionals have been doing webinars just like we're doing today - they have provided toolkits for individuals, and other organizations like Angkor that works with the provider agencies for DSPs has also been doing training. So if you are a DSP, make sure that you're getting access to that information. If you are an individual who relies on a DSP who comes into your home, whether it's daily or on certain days, make sure that you sit down and have conversations to talk about what's what and what's okay, what's not okay and as you direct your services that you are having those very important conversations.

The last thing that I just want to mention before I turn the microphone over is that from our point of view as developmental disabilities councils and many others, we work throughout the year at the state level around planning for emergency situations. Now, typically those emergency situations are things like hurricanes and tornadoes and wildfires and so many other things that have been happening in our country, unfortunately on almost a regular basis, but what we've learned in the disability community is that when you're at the table, when your voice is heard and you are making plans, the recovery is faster, the recovery is better, less time for people to lose supports and services or to be without medical care, to be without family, to be without their supports. This situation of course is a little bit different because, it's sort of upon us and we have to kind of go through this bell curve almost of waiting for it to hit and it's sort of hitting in waves in different communities - it hits its peak and then it will start to come down, and the experts are telling us this this bell curve could stretch out for a period of six to eight weeks, maybe in some areas even twelve weeks - we don't quite know yet. But if you are somebody, I know we're gonna hear in this webinar from some real experts and emergency planning, if you know what the plans are in your state or your local areas, follow those protocols. If you have things like a to-go bag packed and ready just in case you need to move someplace else where you feel safer or need more care or if you do need to make sure that you have enough water that you have enough food just in case things should take a turn in your particular community, make sure that you're following those protocols, and then of course as we all hopefully start to recover, as our nation begins to recover - hopefully just a little bit later this spring, think about some of the responses that you had: how did you feel throughout all of this? What did you learn from all of this? And share that back with us - let us know, let those who are doing that state planning, could be your DD Council, it could be your University Center for Excellence and Developmental Disabilities, it could be the folks who are going to be talking with us in just a few minutes. So make yourself some notes or mental notes or what have you so that we can learn from this experience, because sadly, I have to say, it might be a first of this kind of experience but it's not going to be the last. So the more that we know, the better we are prepared and then the less stress that we all have. So I also just keep encouraging you to breathe, take it easy, be extra kind to yourself, get some rest, keep exercising if that is something that you do regularly, and don't let this take over your life. Just continue to do the things that are important to you and stay healthy. Thank you.

>>Philip Kahn-Pauli

Thank you, Donna, and we'll get to Lori and the partnership shortly, and I really appreciate that piece about - I think there's a couple different dimensions of community health and I think that checking in on our friends and neighbors and co-workers who may have higher physical needs and may be self-isolating for self-care reasons - I think that piece of checking in on them every day is so important. I will just say that we have a colleague who runs our California work and he has a personal care attendant - he has been very diligent about making sure that he is avoiding outdoor activities but that wears on people and it's important that our friend and our co-workers our loved ones. I also think - I'm just gonna geek out for a second before I talk to Lori is, I think that information is also a kind of a newer dimension of community health. I mean, I was totally guilty of retweeting a fake news site that claimed the Pope had Covid, so [LAUGHTER] That is not a good website... the modern information base we live in, getting good information from trusted sources is important, and if you want to kind of a quick primer on the ways that Covid19 really touches on the - unique needs and experiences of the disability community, I highly encourage you to check out Andrew Pulrang's recent article in Forbes which we've got a slide up, well - the slide has a quick summary of the five things you need to know about how this disease is affecting people with disabilities, and it talks about the health risks and it talks about kind of how there's new perspectives and urgency to long term disability issues. I mean, how many people with disabilities have been advocating for telework and tele-learning for years and then suddenly, Harvard says "we're going to all online classes!" So I think that's a good article to go to and get yourself educated on these dimensions, and so I want to take a step forward and go to talk to Lori. Lori you're from - I'm gonna switch to your bio. Ok, you've been a thought leader in diversity and inclusion, and talking about bringing good mental health practices the workplace so, I want to touch on kinda the stress and anxiety of what's going on and how we can take care of ourselves before we get to the kind of the preparedness piece.

>>Lori Golden

Thank you, Philip, and I'm gonna underscore some of the points that that Donna made and you, Philip, are a case in point - as you held up on what not to do. So I've kinda broken this up into four key points, some of which are reinforcing, some are a little bit different. The first is to keep informed - but not overwhelmed. So, when I mentioned Philip is a good case of what not to do - as we all know it's really important to curate the media that you digest and to learn what sources are neutral and what sources are trusted. Some sources, media outlets that we all go to every day, are in the business of driving traffic through creating headlines, and those headlines therefore can be even more alarming than they might - the plain facts might be. So, if that's the case - if the local news is saying very very scary things, then look at your daily local newspaper, look at what the local health department is saying, look at community resources that'll tell you what's going on exactly in your community, but limit your exposure to those that sound histrionic or alarmist. By the same token, we all know people who are - I get confused on glass half-empty or glass half-full, but people who are really pessimistic and who are downers - the Eeyores in our lives, limit your exposure to people who talk and think and frame the world that way, because - I'm not saying cut people out of your life, but be self- protective in how you take in information, and no matter what information you take in and from whatever sources, might be wise to just limit it, because too much can be too much and overwhelm even the most practical, well-adjusted person.

The other that Donna touched on a lot is take reasonable precautions and she mentioned some and some are up on a slide Philip put up so I'm not going to mention that, and she also mentioned take care of yourself, and I would go one step further and think of it as developing your own personal health care regimen. And it's nothing fancy, it's things like hydrating even more than you might otherwise - with any kind of illness that's always a good precaution. Obviously good nutrition, good sleep, hygiene, exercise if you do and if you can, and if you can't, do the next best thing and that's stretch. And if you can go out and get some fresh air, that's incredibly helpful both for getting your oxygen going and just in terms of getting endorphins going and being a mood-lifting experience. Make it a practice to take breaks from anything that's overly stressful: whether it's work that's stressful, it's people in your lives and the responsibility - if you're at home with family that isn't accustomed to being together all day, every day in close quarters, and some of those folks are dependents and have a lot of needs, like children - that in itself can be an added stress and recognize that, obviously you don't want to get away from your children and you want to be there with your family members, but be judicious in how you spend your time, and to the extent you can, take a few minutes of break time to just reset and re-energize. And the other which is pretty obvious but can be tempting at least in some of the more benign ways is over-indulging. Avoid... this isn't a good time to take in harmful substances nor is it a good time to do things you'll regret like over-overeating and getting into cycles where you feel sluggish and you feel down and disappointed in yourself. So treat yourself like you're in training to - not training to do battle but in training to be in the best shape you possibly can be to stay well for those you love and and care about and for yourself.

The other thing I'd say is, and Donna mentioned the importance of planning, I'd say have plans A, B and C. One of those plans is around working at home or, if you have children at home and they need to go to school at home - they need to do class work virtually, think about how you're going to prepare for that and carve out space and keep noise and distractions minimized so that everybody can kind of coexist together most comfortably. Plan for the needs of anybody who's depending on you and anyone who lives in your household: that includes pets and includes elderly family members who may be depending on you even if they don't live with you - think about what their innate needs might be and to the extent you can, put plans into place so that food, medicine, doctor's visits... are available. Any essentials that aren't already in your house - think about how you can get those: lots of medicines can be delivered... these days. Yes, it costs more money, but our health is worth it. Groceries and a lot of products and a lot of necessities can be delivered. So, think of the terms of those things. Doctor's visits, lab tests, therapies... think ahead to what might be in your calendar or coming up days, weeks, or even a few weeks from now and plan for your contingencies - how you're going to get those things done. At my firm at EY, we have a wonderful benefit where we have access to telemedicine, and if we really need to see a doctor, we won't necessarily need to and be able to see the doctor where we're accustomed to seeing but we have systems that allow us to access a physician, a psychologist, therapist, at any time virtually. So think in terms of what you might have available to you and try to put plans in place.

The other thing I'd say, the final point is to proactively manage the stress that you and those in your life may be feeling. The first thing is, and I think Donna pointed to this, reality-check your fears. When your mind starts running and, many of ours do, and if you tend to go to worst-case scenarios, try to stop yourself - check yourself - and do that for others, and try to reset to what you know is a fact, is actually happening, and stop going to what you may imagine. So you interrupt the cycle of taking the worst to the worst to the worst. Also deep breathing - it sounds so trite and so incredibly obvious, but there's actually science behind it: when you take regular deep breaths you are kind of actively interrupting the fight-or-flight response that leads to panic and increased stress, and what you're actually doing is calming your whole neurological system and sending signals to your brain that it's safe - you are safe, things are okay, and you want to develop habits and patterns that can do that for you as much as possible - and we all have different things that that calm us: music - sometimes calming music, sometimes it could be hard rock that you find soothing - we all we all groove to a different beat. But whatever you find calming and distracting, think about employing it. Beauty. I find looking at anything that's beautiful - even on my computer - from beautiful photos to artwork, really inspiring and energizing and it can lift me out of a sort of cloudy mood. Small pleasures - we all have, we call them guilty pleasures, some of them we each feel guilty about than others, but whether it's a food that you wouldn't normally eat that you have in your refrigerator and you've been saving and you've had a stressful time and you eat a bit of it or you sneak some time to watch a television show that you're ashamed you watch but makes you feel good or whatever those small things, are provided they're not harmful to you or anybody else - take advantage of those small things. We often call them simple joys - many of us... there was a joke years ago about people looking at cat videos, looking at pet videos, looking at small kids - there is a reason why, at the end your local news segment - and actually national news segment, there is always an uplifting story. So whatever is uplifting to you or inspirational - it can be inspirational short stories or true stories, it can be uplifting movies with happy endings, it can be - I opened the paper this morning and there was a picture of fuzzy chicks, baby chicks, and it made me smile, made my heart feel glad - so look for these things. If you're lucky enough to have pets and those pets aren't a total pain all the time - pets can be tremendously calming rewarding and relaxing. A lot of science behind gratitude journals - just thinking about what you're grateful for. To some of us that's hokey, to some of us that's very helpful. Creativity. I find doing something creative - making or doing something, creating something out of whole cloth - I find to be really energizing and takes my mind off of whatever's concerning me. And the final thing I'd say is connection. It seems a little bit counterintuitive because on the one hand, we're saying if you don't feel well or have symptoms don't get too close to people, maybe don't go out of the house depending - however keep in mind, the old saw laughter is the best medicine - laughing especially with friends and family is one of the best things you can do to calm yourself and relieve stress. So when there are opportunities to do that - if you're with home at home with your family and you can watch a silly movie together or play games together or look at old photos that make you all smile and remember things together - that can be really really helpful. The other thing is helping people. Many of us find that reaching out to others and giving back is a great way for getting out of our own headsets and our own worries. And making a difference in the world or getting involved in things you care about whether it's a cause or an organization or it's a political campaign or it's something abstract or just reaching out to an individual who might need support - anything that takes you out of yourself, not only takes your mind off of your worries but gives you a sense of agency and control, when what all of us are feeling right now is that loss of control, that loss of routine and that loss of certainties. So, I urge you to kind of think about what makes you feel good and be really conscious of giving those gifts to yourself and to those that you love to try to feel better and do better.

>>Philip Kahn-Pauli

Gotcha. Well thank you very much Lori, I think that's all very simple but very practical and you know, sometimes the simplest things are the hardest and the most important. So thank you for sharing all that. I'll say that that last piece really resonated with me in terms of helping others - we may not be able to go out... they may be discouraging you to go out to large crowds but we still have... the disability community is very large, very active and very online so we may be able to shut ourselves up in our homes but we should make sure to keep those social connections alive online and I keep thinking about my - I'll just say my wife works with foster care youth in DC, and they're very worried about what's gonna happen to all of those families they serve if school shuts down and so her organization is already kind of thinking about well can we do a book drive or collect board games or do a food drive to help our families in the event that they get shut in for a while, so I think that last piece of trying to find ways you can help others is good self-care and good community care as well.

Before I get to our folks from the partnership I do want to quickly answer two quick questions that came from our audience and I'll go with the second one first and then the first one second, so the second question we had was in what ways do you anticipate Disability Employment to be positively or negatively affected by Covid-19 in the coming months. I'll offer my perspective and Lori or Donna if you want to jump in after I say something please do so. I think obviously the uncertainty in the marketplace could lead to a recession - I don't want to go that far, it is what it is. I think in a short term it could be bad because a lot of people with disabilities end up working in the retail sector which has a lot of interpersonal contact, not much in the way of paid sick benefits or sick leave, but in the long term, if more companies realize that telework is a very viable way of meeting their company needs, getting the work done, being accountable - if a future employee with a disability were to ask for a telework plan in the future, I think that you know a lot more companies having a lot more experience using technology to basically ensure productivity in the workplace I think that that could ultimately be beneficial in the longer term - but that's a very long term, much further ahead than we can really look at the moment, and that ties into the second question, which - the first question which I don't really have a good answer for - one of our anonymous attendees asked if a workplace doesn't permit working virtually can this count as a violation of disability rights? I will quickly say that I am NOT a labor lawyer I am NOT an ADA lawyer, I don't know if it would... I know that failure to provide accommodations is one of the common reasons why things end up in front of the EEOC. I think it would be very dependent on who was the employer, what was the work being done, so I don't have a good answer for that, Anonymous, but that's the answer I have for you. Sorry.

>>Lori Golden

This is Lori. I'm not a labor lawyer either but I'd add - I certainly agree with everything you said, I'd also add it depends on the nature of that person's disability. So working from home as an accommodation for a disability is dependent on the disability. If, for example, you are hard-of-hearing and you need to, want to stay at home because of Covid19, being hard-of-hearing and qualifying or being deaf for that matter, as a person with disabilities, does not necessarily qualify you to work from home as an accommodation. It needs to directly relate to mitigating the impacts the disability. If, however you have rheumatoid arthritis, where the immune system is compromised and going into a public setting might put you at substantially increased risk, that might be a different story. So my caveat would be it also depends on the nature of your disability and it's impacts. Got ya. Donna?

>>Donna Meltzer

Yeah let me just jump in as well and I too am NOT an employment lawyer but I think that, within the scope of Covid19, most employers are looking at what their state is telling them, what the CDC is telling - you've heard the terminology you have underlying health conditions, right? People who are elderly, people who have underlying health conditions should be taking extra precautions, should be staying home, should be really mitigating their risk. So I think - I can certainly tell you around Washington DC, traffic has been incredibly light, many organizations have given all of their employees the option of working remotely if they feel that their health could be compromised or that they may compromise others - so I think that there's a lot of leniency going on right now, but it may vary state to state. Depending on you know where you live and how many people have been impacted in your state, are you in a more rural setting or are you in a city, are you working in a busy area in a city with lots of people in an office - I would suggest that if you were a person with a disability who is really concerned about this, have an immediate conversation first with your supervisor and then perhaps with the human resources departments. Because what I'm starting to see is a lot of companies, organizations, nonprofits - come out with different standards for the duration of this virus which may be with us for a couple of months, but they're really actually even encouraging people to work from home. Again as Lorie said, it also depends not only on your disability but what kind of work do you do And what kind of business in what kind of business, right? So if you're an office worker and everything that you do can easily be done remotely from your computer at home, I think that you're going to you, with a simple conversation get the clearance to work from home. If you work very front-facing in a store, you're working retail, you're working for a factory, a company that your job is essential every day to be there physically - that might be another story and then what you want to do is ask the HR department, what is your protocol, what are you -- what steps are you taking right now to keep your employees safe - I feel like I might be at a higher risk, can we talk about that? Gotcha.

>>Philip Kahn-Pauli

Thank you. And so we've been talking through everything and I do not want to neglect Shaylin or German, so I want to thank Lori, I want to thank Donna and shift gears to talk about the emergency preparedness piece of it. So for those of you who are not familiar, so German and Shaylin are the co-executive directors of the partnership for inclusive disaster strategies which is a really fascinating organization that is at the cutting edge or whatever metaphor you want to use of disability inclusion and emergency preparedness. It's very much an evolution out of the leadership of Marcie Roth who worked at FEMA for many years on responding to disasters and making sure that people with disabilities were not left behind, forgotten isolated institutionalized and the partnership is really really you know as I said at the forefront they are really doing some interesting fascinating important work and I want to thank them for joining us and I've already talked you up a little bit so I'm really curious - can you talk to us about what you're doing around Covid-19? You've got a national call to action out there wondering if you could talk about that or talk about ways that our listeners could get involved donate or help spread the good word of what you're doing.

>>Shaylin Sluzalis

Thank you so much Philip, this is Shaylin Sluzalis and with me is German Parodi who as Phillip mentioned we are the co-executive directors of the partnership for inclusive disaster strategies, and our organization really does focus on the disability rights inclusion and accessibility throughout all phases of disaster operations and emergencies for people with disabilities. With that is - we know that community resilience is only possible when planning response and recovery is accessible to all, it includes people with disabilities and others with access and functional needs as key members of community preparedness and resilience initiatives before, during and after disasters. And with that we also know that people with disabilities are two to four times more likely to be injured or die during a disaster, and in this case a public health emergency which is now declared by the World Health Organization as a pandemic is a type of disaster. So with that, we can anticipate that people with disabilities will be systematically disproportionately impacted during these very unknown and continuously developing times, especially when we have things as was mentioned earlier like misinformation, inconsistent information, and fear spreading. So it is important that our communities are getting prepared in this case for systemic disproportionate impact. So in preparation for, in anticipation for that, system advocates, disability organizations, a coalition of disability rights and inclusive emergency management experts came together from across the nation and issued on March 3rd an urgent call to action for immediate strategies and solutions from the federal government and governments at every level, including local, state, tribal and territorial, to address the specific needs of people with disabilities throughout the Covid-19 outbreak in all public health emergencies. And this national call to action really calls upon the emergency and health strategists to address continuity of services for people with disabilities who require them for their health and daily functioning, access to actionable information for people who require accessible forms of communication, including vision or hearing disabilities, intellectual and developmental, cognitive, learning, hearing, reading and information processing disabilities, ensuring that daily needs of people with disabilities are met for food, housing, health care and community support, which are provided by personal caregivers or community agencies. We also mentioned how to operationalize the living arrangements throughout quarantines that potentially may be particularly burdensome for people with disabilities and their families, and also to ensure that access to necessary tests and protective equipment is available, not only to people with disabilities but to their caregivers and takers, and the provision of training for agencies and their employees in their legal obligations with regards to people with disabilities and including and in communicating with disability community leader subject matter experts.

So we know that there is a workforce crisis already existing before Covid-19 started in regards to direct support workers, personal care attendants, and we do fear that this Covid-19, this health emergency may dramatically exacerbate the workforce crisis. So we were really calling upon the government to take systemic actions to be as prepared as possible to respond to people with disabilities and the inclusion of people with disabilities at the planning table - that voices are being heard, as well as needs and rights being met, and those legal obligations being fulfilled.

So actions that we can take - as Donna mentioned earlier talking to your local public health officials, your state emergency managers, disability related providers, you know - ask them questions. What are their contingency plans and continuity of operations plans? How to address in home and community-based services and supports if workers do get sick or don't feel safe? If the consumer does not feel safe, the person with a disability - or simply if somebody does not have a support network - what are those plans for those people that may fall through the gaps? So asking your local, state providers, state agencies, emergency managers - asking those questions of what are continuity of operations for things like home and community-based services, accessible communication, and access to medications - the things that are very vital to daily independent living needs in the community.

Some legislative advocacy that we could bring light to as system advocates and advocates in the disability community is there has been since June of 2019 a bill called the REAADI for disasters act. And REAADI stands for real emergency access for aging and disability inclusion and those bill numbers are HR 3208 and S 1755. And the REAADI for disasters act really does address a mire of disability related issues in disasters but specifically from the Covid-19 outbreak, pieces that we could start advocating for in our communities with our congressional leaders is federal funding for nonprofits and centers for independent living to do the work that we are all doing now for community preparedness, information and referral response requests - those things that are happening because we know they need to happen or people will fall through the cracks, but may not be federally funded or funded in any matter with financial support. So REAADI would address that issue specific to disaster and emergency related response for nonprofit organizations, as well as the training and technical assistance for funding if this comes in that federal agents - if federal agencies come in like we are seeing at the National Guard in New York starting to come in. If this outbreak comes to the extreme of needing more federal agencies involved in filling these gaps such as in-home supports and services, that they have the proper training and technical assistance to understand self-determination and people with disabilities's rights, and just properly working alongside of people with disabilities. So we encourage folks to take the REAADI for disasters act to their state legislators, to Congress, and to advocate that these pieces could be replicated in your local area and certainly we are advocating for them on a federal level. There are other legislative efforts underway for things like paid sick leave. I'm not entirely sure if that would cover consumer directed personal assistance services, but we have not seen specific legislation on the needs and rights of people with disabilities in disasters or public health emergencies, and REAADI for disasters Act does begin that discussion.

So of course as everyone has mentioned getting personally prepared. As if any other disaster is coming to knock on your door, get your plans out and dust it off the shelf. Start communicating with your community support network, your friends, family, support workers and the community about what your plans are in all scenarios and especially in the worst case scenario, so that you know that you have a plan in place with the community around you, and of course advocating on a systemic level as well for that.

>>Philip Kahn-Pauli

Definitely. And Shaylin, I just want to quickly interject I've included -- in the chat box I've included a couple links that gives him background on the REAADI link as well as the sign on letter for the partnership's national call to action, so... And I will say that just this morning the Consortium of Citizens with Disabilities had a membership meeting to talk about some of the advocacy around the House Democrats' proposal on paid sick leave for workers impacted by this crisis, so I know that there are advocates that are pushing to make sure that DSPs are included, but, you know, it's an evolving situation and as Rahm Emanuel once said, let no crisis go unused so or he said something like that, but I really appreciate it. And I was gonna say, Shaylin, the partnership has responded to a wide range of different emergency situations before, so I'm kind of curious - can you kind of take a step back and talk to us about kind of the scope of work that you've done and what are some other things you're working on?

>>Shaylin Sluzalis

Yes absolutely. The partnership was created, as you mentioned earlier, with the lead of Marci Roth who was previously at FEMA's office of disability integration and coordination. And through that actually the partnership was formed out of Port Light strategies which is an organization that focuses on response and the need for disaster and disability inclusion in the response efforts of disaster. So Portlight Strategies has been around since 1996 and has been responding to things as wide as the Iraq war, to Haiti, and to Hurricane Maria most recently where German and I began to get involved as Portlight Strategies asked us to deploy to Puerto Rico after Hurricane Maria and specifically focusing on the needs and rights of people with disabilities, and reaching the folks that are in the most remote areas that may not be able to get to distribution points to the food and water that may be coming down the street, but folks that aren't able to get out of their home to get that. We really focus on filling the gaps in the needs that are there that we're able to identify with our partners across the nation. So we have many partners that help us do all of the great work that we do what to provide durable medical equipment and consumable supplies after disasters. We were most recently in in the Bahamas after Hurricane Dorian, providing relief and durable medical equipment and consumable medical supplies to keep people independent and at home with dignity and respect and independence.

We also have national disability rights stakeholder calls on a weekly basis on Tuesdays, where we encourage many stakeholders from emergency management levels to community organizers and advocates to get in a discussion on how best to prepare. What is disability inclusion in emergency management and disaster planning and the before during and after piece. So we focus on all aspects of a disaster in emergencies, all aspects of -- and all disabilities, all ages, all children, and just any type of disaster related need in regards to people with disabilities, we try to fill those gaps, fill those needs. And with that is also our disaster hotline that we have available to the nation that number is 800-626-4959. And we encourage folks to reach out to us in in any area of the country that is impacted by any disaster with any disability related need, and we will work with individuals to connect them with the resources that can can fill those needs.

>>Philip Kahn-Pauli

Thank you so much and I know that we're running kind of towards the end of the hour that we had blocked off. I will make sure that both links to the scope of the partnerships resources as well as copies of the slide get distributed to everybody who is online today.

So for our audience I just wanted to quickly give a shout out. I know you've already asked a couple questions. If there were any other further questions that our audience was burning to ask, now is the time to do so. "What steps should people take if they need to move states with a disability during this time?" That's a big one, of course it would depend on the person's disability or their need, and I think it's one of those questions for the family members of - is now the right time to be making a drastic choice or decision like that? Do any of our panelists want to add to that or...?

>>German Parodi

This is German from the partnership and to those of us that are Medicaid dependent, it is - we need to understand that it is not just not across states so if you are looking at that, perhaps calling a DD Council in that state or a center for independent living in that state to begin addressing that. And for the sake of time, in the REAADI.com website, you will also find information of the disaster relief Medicaid Act which completely covers in disasters, having Medicaid follow the person across states. It is a big issue but just to note that if you do have Medicare that does cross state lines. And surely ACL's website on it has more information on this, and CDC but there is a great issue to be aware of.

>>Philip Kahn-Pauli

Yes and thank you for that. Yet again, it goes back to the point of we want to make sure we have good information and we're trusted sources from CDC directly, from ACL, from the DD councils, from your state and local providers, not random social media accounts that are unverified. We got a different question from Sudhi - I'm not going to try butcher your last name, apologies. "We offer many lab type courses and campus may decide to keep those courses running. What steps do you think that we should take for the safety of our students, staff and faculty if they do stay on?" I mean, I think we kind of already touched on it in terms of, remember - wash your hands for at least 20 seconds. Pick whatever song you want to sing to sing it while you're washing your hands, scrub very thoroughly. If you can get your hands on it hand sanitizer is kind of important, you know - killing the virus requires precautions and safety. If any of the students staff or faculty start showing signs of a fever or cough, encouraging them to work from home. I know that may not be possible if say it's a lab course where you're actually growing fungi in a lab or something but, you know, I'd say having a buddy system might be a good idea where everybody is responsible for everybody else, and if you haven't heard from somebody in a day or two check in on them. That community health piece of checking in on everybody and making sure that we're all doing what we need to do to take care of ourselves and others is important. Anybody else want to offer anything else for Sudhi?

All right there being none, I am going to say thank you so much for our panelists. Thank you all for joining us and lending us your expertise, your insights. Thank you all of us who joined us for the webinar today. I hope that you have taken away the key message of don't panic, wash your hands, take care of yourself, practice good self-care, get good information, share resources, sign on to that call to action, learn about the REAADI act and maybe there's some legislative opportunities out of this crisis, and you know - let's kill the virus, and remember to call our mothers and take care of everybody, okay?

>>Donna Meltzer

That's great and I love the suggestion to sing happy birthday to the ADA when washing your hands,

>>Philip Kahn-Pauli

There we go, happy birthday to the ADA.

[Crosstalk]

>>Donna Meltzer

Thanks for a great opportunity Philip, we appreciate RespectAbility.

>>Philip Kahn-Pauli

Thank you everyone who joined us today.