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# **Emergency Preparation: Innovative and Inclusive Strategies Transcript**

## **October 13, 2022**

## **1:30 PM E.T.**

>> THE MODERATOR: Hello, everybody. We'll go ahead and start this off with some housekeeping stuff, as if you haven't heard this before. I'm Sidma madden, a board member and treasurer. Thank you for joining us about this workshop. You're here to hear about emergency preparation. I want to mention a few housekeeping items before we get started today. When you scroll over the screen, a menu bar pops up. Depending on what device you're on, you can find that bar at the top or bottom of the screen. That is where you will find the closed captions for today's session. View the captions by selecting the cc tab on the menu bar. For sign language interpreting, you can find the interpreter on the screen. If you would like too change the size of the screen if slides are shown, select the line in the mid Tom make the slides larger or smaller. If you have technical issues, please use the chat feature. You can find the word bubble in the same menu bar. If you would like to turn the chat feature off if you're using a screen reader, you can do that by pressing alt and H or please use the info section on the conference website. For Q & A times, use the Q & A box in the menu bar. To ask questions or make a comment, select the hand option on the menu bar. It allows us to know if you have a question. For those of you on the phone today or using key strokes, we ask that you press the star 9 or the altY on your keypad to raise your hand. We will let you know that you can unmute. You can select the unmute option or alt A if using key strokes. If you join the conversation, keep background noise down as much as possible so we can hear it clearly. Can with all that said, I'll turn it over to our speakers. Thank you.

>> GERMÁN: This is Germán. Thank you so much. My name is Germán Parodi. I am a board member with APRIL and director. I use he/el pronounces. I am a brown‑skinned Puerto Rican man sitting in my wheelchair. ‑‑ wheelchair.

>> BETH: I am Beth Meyer. I am the Executive Director of the Florida independent living council. I am an older female with long, gray hair and glasses and a very busy bookshelf behind me with all kinds of things on it. I apologize for that.

>> GERMÁN: I am joining you from Philadelphia and where in Florida, Beth, are you?

>> BETH: Tallahassee. Northern Florida.

>> GERMÁN: Thank you, beg. As the conversation goes on in the chat, if folks could put what parts of the country you're in and maybe as the conversation continues, we might touch on specific topics 679 but the innovative and inclusive strategies that we'll go over will begin with the very busy hurricane and wildfire season of 2017. Beth will begin by explaining the activities that the statewide independent living center led with the collaboration of all the (indiscernible) throughout Florida and as that was happening, we began contemplating people with disabilities and centers with independent living and or supporting organizations can be first responders. We're not search and rescue, but immediately after, there are many essential services. You will hear about essential services. At the beginning of the COVID, many (indiscernible) had to provide essential services and we'll touch more on that. But during this time, I know that, you know, with the partnership, in 2017, the leadership of Marcy Roth, who used to be the FEMA, federal emergency management agency office of disability integration and coordinations director for 8 years during the Obama Administration. It created a great collaboration between FEMA and the disability community throughout those years. In the last four years, it had been a little bit absent from the federal side. I will share that FEMA does have, now, a new ‑‑ FEMA ODIC has a new director, Sherman Gillams. He just came in about a month ago. His first appointment now is in Puerto Rico. He just landed there. He will meet with (indiscernible) and focus on needs of our community and collaborate with us. There are good practices coming ahead. Beth, why don't you start sharing what you did once you saw Harvey coming and how you began organizing.

>> BETH: Thanks, Germán. I have been working at a center of independent living or ADA coordinator for a county for many years, 20 plus years, 25 years before coming to the council. So what I brought in is the work that kind of happens at a county. We also closed the department of justice agreement, so I understood what the feds were wanting us to do for this program of disaster response and making sure that it was accessible to all of our citizens in each state. So it has been kind of like an evolution of understanding the process and then really trying to dig into solutions. One of the things we did were reaching out to Marcy and Germán through the department. We had to have someone that was available to us all year to have frank discussions on systemic barriers and why they're in place and how we can better address them and then understanding the roles. So I think everybody sees a little bit more involvement with ACL and discussion with disaster response for ourselves, and I think it's because there's a recognition of the work that's been done and understanding that service a little bit more because it really is highlighted when there's some type of response for a state. So when I came in over to the FILC, the state independent living council, I started in 2018. About two or three months later, hurricane Michael came through. It was a cat 5. We went to bed and it was a cat 3. We woke up, and it was a cat 5. It was not a good situation. So we began hosting daily calls because we didn't even know whether or not our center in Panama City was even there or the people were alive because there were people that were ‑‑ had perished. It was a direct hit. He scrambled to understand communications and what do we do and how do we do it. I had just literally started this jobs, so I had a lot of opinions. What was in place and what we did were more of a defensive type of reaction to everything. We would get calls and people posting stuff on our Facebook page, and I immediately tapped into Marcy and Germán and Shaylin and could you help me out here because there was no FAQs that I could pull up and reference. And then I knew what the CIL did because I worked at a CIL. In this type of disaster, it was not ‑‑ we did a great job, but there was a lot of catching up. So after Michael, we had ‑‑ many March, we had a round table discussion of ‑‑ for the CILs. Everyone of the CILs participated. We had a discussion on, like, what is real? What do we do before a storm? Let's be real about this. And what did we do during the storm? And what did we do after the storm? Three things. This is where, when you have a discussion, you bring in, you know, the partnership and because they're able to be a third party and help guide the conversation to where you need to go. So what we did was had everybody at the table. We talked about all the things that we did in preparedness and ‑‑ throughout the storm. Then we said, okay, let's go back. What should we have done and let's just be honest and say this is probably what we should have done and let's do that for the preparedness and let's do that during and then let's ‑‑ because we're not first responders in the sense of what a first responder (indiscernible). What do we do afterwards. We looked at that and created pretty much our goal for our state plan, which is, you know, very specific to the work we do, and captured all the work that we discussed. That goal four talks about collecting data on do you have a MOU because that was something we talked about. Are you reaching out to your counties? These are all the CILs. And do you have a relationship with Red Cross? Do you have a point of contact with Red Cross? We put these in our spiel, so we've been collecting this data. It allows us to talk to the CILs that maybe are doing less and try to understand why and then ‑‑ and get them to where we need to be as part of a network in the state. 15CILs. Four solid other satellite offices and then in covering 65 counties in the state. All both part B and part C CILs. We really had to kind of dig into roles and being strategic where DME was, understanding how we could provide trainings and assistance during blue skies, getting MOU's with the counties for possibly interpreter services or at least connecting them with that, understanding who that ADA coordinator is and you have an active ADA coordinator, partnering with them so that they understand the value. There's a lot of work to do all year to prepare for a storm. Provide examples of, you know ‑‑ we came up with examples of possible additional training from FEMA that we needed. We would consider ‑‑ the CILs could consider to have a staff member take and participate in and identifying a staff member that would play an important role during a disaster, having the understanding that they're calling the consumers before a storm and then making sure that another CIL could assist you with following up after the storm if your CIL was impacted. Like do you have a partner? Do you have a CIL that's in close proximity that would be able to call your consumers for you because you might sustain serious damage? We had four CILs directly impacted from this last storm. One of the CILs, their building is gone. That CIL is in northeast Florida. We get to have the daunting task of understanding when a hurricane comes in, it comes into ‑‑ it pretty much covers the whole state. So everybody is somewhat impacted. Everybody is always somewhat impacted, but then there's some CILs that are more significantly impacted. So we have four buildings that were ‑‑ sustained some level of damage. Some, not so much. Some, not bad at all. Our Ft. Myers CIL is up and operating with limited wi‑fi, but it was not damaged near as bad as the Sarasota and Daytona CIL. It's been able to send teams in to help the CIL that's it the hardest, call the consumers. You might have to share your consumers. So, you know, at least we know where they are and to be able to assist. A storm ‑‑ a hurricane and fires are the same, I know. But it requires cooperation. It commands that you cooperate and you work together. So we have these daily calls that were started with hurricane Michael. Germán and Shaylin are on these calls. Marcy is on the calls whenever she can. FEMA is on the calls. Red Cross is on the calls, and we handle problems that are real time, and we provide solutions to the CILs then. So Germán, do you want to add to that?

>> GERMÁN: This is Germán. Thank you for that overarching framework. Thank you for sharing where you're joining from. We have folks from a stew statewide independent living councils from Georgia and New York and Idaho and colleagues from North Carolina, Michigan, and eastern Kentucky, from hazard, from Utah, from Montana, and from north Florida. As Beth was explaining, delineating your ‑‑ what you do in state to state and joining that with what will your consumers need in a disaster? What type of a disaster? A disturbance to essential daily services, access to medication, access to transportation, work, education, personal assistance. Your daily activities. And this could be from a storm or a flood or an earthquake, from a fire, wildfire, from a blizzard. Certainly think also about power outages and extreme heat, at it will go on throughout the country year after year. Extreme heat puts a strain on the electric grid. Power outages will be something that we need to prepare for. And localized fires. We don't need to ‑‑ disasters in the term that the local county and state cannot respond to the needs and causing a federally declared disaster. We here ‑‑ and you ‑‑ perhaps deal with building and house fires. You're dealing with transitioning and intervention. That in itself, for that person, is a disaster. And that micro wraparound service that you're working to get, the person out of the institution, they need to get that housing and those first payments and those first utensils to get them going. But across the board and to accomplish that we need, as Beth delineated, a great example is having in your (indiscernible) at the statewide independent living level emergency preparedness response. As through COVID, many of you and many centers for independent living did vaccine sites and other services, delivering feed and other essential items. Those relationships that you have developed with public health, don't drop them. Continue them. Beth, why don't you share some of the successes through COVID, perhaps, early in 2020 when we did not have a vaccine still. Our community where ‑‑ at the margins of response in the initial faces of quarantine, how many people were without personal assistance, food and water deliveries. Let's not forget ‑‑ remember, during the summer, that the ‑‑ the killing of George Floyd. It's an awful ‑‑ and we need to stop such crimes from police force and discrimination to black communities. But the civic disturbances that came following throughout the country ‑‑ I live in Philadelphia. And how would we get the personal assistance and essential needs during those moments to our consumers. Beth.

>> BETH: Thanks, Germán. I'm going to start what we did with COVID with just a quick ‑‑ I'm going to read you our goal four. I'm not reading you the activities. Don't worry. It's the spiel and we know how those activities go. Goal four, this is what we have. Disaster preparedness, response, recovery resulting in systemic change. People with disabilities will have equal access to the community resources as a result of a disaster. Then we put natural, such as a hurricane or pandemic; human‑made, such as terrorism, civil unrest of mass shooting ‑‑ we put that in there ‑‑ or technological, such as a chemical release or power outages or mass cyber security breach. We put that in before the COVID response because we wanted to make sure that we were at the table if there was something that happened. We had already had a shooting down at the pulse club that was ‑‑

>> GERMÁN: Pulse, yes.

>> BETH: I couldn't remember it. Thanks. That had already happened, and we wanted to make sure that we were being ‑‑ exactly like Germán said, there. And what does a disaster look like? It doesn't look like necessarily a hurricane for a lot of people. What we did was COVID provided us a great opportunity in our mind for a stalled storm, and that's how ‑‑ that's what we would call it, a stalled storm. It's very hard to come up with really great solutions during an actual disaster, but we were able to really dig in to opportunities during COVID 678 there was this systemic barriers such as transportation needed 48 hours to set up rides, yet the COVID shots were being announced at some of the pharmacies and you got about 24‑hour notice and that was coming out of the department of health. How can we address that? And this was leaving us out of the ‑‑ we were removed from the table by that systemic barrier. So when we brought it forward to them and understood, you know ‑‑ and we have a seat in the EOC. I don't sit in the EOC. I'm in the EOC because we provide answers to their most complicated services that they're trying to provide and who they're trying to assist. Our CILs can do that for them. So we're in the EOC during this time. So we went ahead and had some CILs come up initially at the beginning and work in the EOC. We cannot do that. They worked in there and were part of the team and got to understand what was happening so that we were able to work with our local transportation and get a food delivery to all ‑‑ to our consumers. So the transportation that wasn't running initially ‑‑ because everyone was staying at home, was able to still do work by delivering, with their centers, food to people that will we said stay home. We're talking about sheltering in place is what we're talking about. That was very important, and so there was over 23,000 pounds of food delivered to CILs in our state, to be delivered to the homes ‑‑ to their homes. Durable medical equipment went out. We provided virtual benefits for the SNAP/EBT cards. We set up virtual opportunities to work with our consumers and working through that and still providing the critical things that happened that they needed assistance with that we could help. Our CILs did all of that. They held virtual gatherings because isolation was, like, a big deal, and it was impacting our community and so we started seeing virtual gatherings rolling out. And then really working with the local transportation to make sure that some of the healthcare services and those doctor's appointments weren't being missed, that we were able to work with them on that. Then what we saw is receiving the vaccine was a barrier. It was a problem. So we asked can we open up our CILs as vaccine sites. We had been a very good partner during Michael and we had been a good partner during the first part of COVID. We asked to open the CILs up. Whenever CIL that wanted to participated. They all wanted to. They might not have offered it in the CIL. They might have offered it in a local church parking lot and it was a drive‑through vaccine that they also could get food, they could also get other resources, you know, literally provided for them and begin to them in their car. So 13 of the CILs actually ran ‑‑ they were operating as COVID vaccine sites. They had multiple days that they would do this, and they would have the department of health was in charge. We had a vendor, CD McGuire, that worked down from Miami that sent out their nurses. They were the ones working under contract with the department of health. So our CILs were making sure that the facility was accessible. Most of them were in the CIL and providing wraparound services. There was about 5,000 people that received vaccines. We also vaccinated PCA's that came, you know, with, and that was with of those punch lists with initially the people that were able to receive the shots, PCA's person initially on that list as the priority, but what we found is when they came out, the vaccines, they know, they needed ‑‑ know, they needed to use the vaccines or lose the vaccines. We had our PCA's there and provided the vaccines to people that are a critical part of independent living, the personal care assistants. It became another good partnership. We held one of the first ‑‑ we sent out surveys on vaccine hesitation, trying to understand why not all of the consumers wanted to get vaccinated and then we created med talk. That was a south Florida CIL, created med talk, which is inviting doctors to talk to the community, which is answering questions. We understood why some of the consumers were choosing not to. It was a valid reason and we had to communicate to the department of health throughout the process. We also provided, you know, accessible training at the FEMA vaccine sites. Our CILs were able to go there and assist with that, but we just kind of had to get ourselves to the table and stay there. It was, I would say, very successful partnership for our state.

>> GERMÁN: This is Germán. Thank you. I'm sure that resonated with many on the call. We also have colleagues joining from Wyoming, New Mexico, the Wisconsin CIL, from northwest Iowa, the youth LEAD from North Carolina and the North Carolina CIL, Eva Reynolds shared that they have emergency preparedness included in their North Carolina SPIL. Alyssa did share wonderful work. Alyssa, if you scroll up in the chat, you'll find the link for (indiscernible). In keeping up with all these activities, it's recognizing, essentially ‑‑ you all know this. What do our communities or what do our consumers need to remain independent and as disasters, disturbances to essential services continue to rise, increasing the capacities for centers for independent living. We provide trainings every day. Since 2017, we did deploy a team to Puerto Rico following hurricane Maria and have been collaborating ‑‑ we've supported there with the center is of independent living daily, connected them with FEMA. As bent has done in Florida ‑‑ Beth has done in Florida. Puerto Rico doesn't have a CIL. They have two centers, one in the capital. Since Maria, they have included ‑‑ immersed themselves heavily into emergency management and public health at the state level, involving local collaboration throughout the counties and looking for what are the needs of your consumers. Not only the stability related needs but information, thus, making things accessible, as you would in sign language and in different languages; not only, perhaps, Spanish, but looking at the census, looking at your county, looking at what are the most used languages in your county and maybe including the question for your consumers. And specifically in disasters, as we always ask and is mandatory with the ADA but having emergency services have ‑‑ emergency briefings on TV and radio but specifically on TV having ASL on. It starts at the beginning. It starts at being informed. Just to a couple more examples from success, in 2020, in January, just ahead of COVID, there was a massive earthquake in southwest Puerto Rico. Through collaboration with emergency management, the rescue ‑‑ two people with disabilities were much focused, something that didn't happen in Maria. It saved lives. Two weeks ahead of Ian impacting Florida, a hurricane impacted Puerto Rico. (Indiscernible) is meeting, as I said, in a couple of days with Sherman and finding a need for consumers and looking for a way to support them at the moment of the disaster in their need and preparing them through your staff, consumers, fully involved community, looking for organizations and the essential government entities that you need to develop relationships with. We've gone through a lot and we want to go through some of the examples that the centers for independent living are responding. There are sales staff in the streets throughout Florida doing activities that we want you to hear, but does anybody have questions from all ideas and examples that have been presented? You can submit your questions in the Q & A box or raise the hand feature, I think, on the keyboard, it's alt and press Y to raise your hands. Karen, on the chat shares our CIL offers services such as life‑sustaining food, water, and supplies during COVID in eastern Kentucky in our service area as well as assistance to connect consumers to healthcare and COVID vaccines we are still assisting our consumers with services since eastern Kentucky flooding. Thank you for sharing, Karen. We, from the partnerships, have been in touch with Brenda and Catherine and working to connect them with FEMA's regional disability integration specialist. All of these terms and ‑‑ we will provide ‑‑ we will put our contacts if we have more interested in learning the technologies and activities. Don't hesitate to reach out. We'll send you more information. Connecting with your artist ‑‑ there's one in every region in the country. If you're not going through, introducing yourselves ‑‑ or we can introduce you to them. It's essential to developing the relationship. They can't introduce you at the local or state level or if you're not having that door as easily opened. Beth, why don't you ‑‑ as you are sharing ahead of Ian, you had already started daily meetings throughout ‑‑ including with Red Cross and FEMA and the centers for independent living and we were joining. How did your centers for independent living across Florida prepare? Did they do contacts to consumers ahead of time? You had about four or five days ahead of the storm to know it was coming and then the immediate response and activities two weeks or so after.

>> BETH: Right. One of the things that we did for our planning was every consumer that comes in is asked in their CSR packet do you have a plan. If there was an emergency, do you plan to evacuate? Do you ‑‑ what is your plan? And try to understand that do you want to be contacted if there is a storm? A lot of the centers have gone to a mass callout that can reach, like, 2,000 people quickly and that mass callout allows them to provide possibly next steps. We don't provide where to go. That's done by your county. You have to let your county own that. That's their job, and you're required to do that. As a CIL, we can ask our consumers are you prepared? Are you interested in learning more about being prepared? A lot of them have emergency preparedness conference that brings people together and allows consumers to be see what a shelter looks like because they're not super comfy and really what you can bring. That activity of providing a ‑‑ in nice weather, an example of what a shelter looks like allows people to understand what their responsibility is. Even has their own responsible, and it is a choice to evacuate unless there's, you know, a mandatory evac area, but people could still hunker down and not leave. But there's not going to be anyone to come get you once the storm arrives. The hard part about this particular storm was that everybody pretty much thought it was going to hit Tampa because that's where it was going, but it started moving left/right, left/right then took a hard right. And that's why a lot of people didn't evacuate. I'm going to get to Germán's questioning, but I want people to think about ‑‑ because this happens in your state with whatever your disaster is. It happens differently but it happens. People that live there think off disasters differently and manage them differently, whether it's a fire or storm or tornado. In Florida, I think we think of it very linear when it comes to a storm. It could hit ‑‑ we know what the difference is. You can be a mile, a half mile on one side of that wall and barely receive anything. It can rain in your front yard and not in your backyard. So what we know is that is community is gauging evacuation on that on that. Exactly where it is going to hit? That's where we need to pay attention. Everybody thought it was going to be in Tampa. When it took that hard right, there's a lot of people that chose not to evacuate. But what you can do as a center and what is a really important thing to do before you get a storm is understanding what do all of the centers ‑‑ what other services do they provide? Identify all of those things before a storm, and this is something you can put in your state plan. Identify all of those services and capture them so you have a game plan and then in addition to that is we do call every day when a storm is coming or there's a disaster. We meet once a week in blue skies. But we meet once a week to make sure ‑‑ just to do a check‑in. It's not mandatory. We just open it up. It has been a very great platform for CIL Executive Directors to compare how they use their public health workforce dollars. How are they using some of their CARES act dollars. It's just a call. You can talk or don't have to talk. Sometimes they chair their challenges that they're having and it does create and foster the environment of team. So when a storm comes and we go to daily calls, we bring in the big people from ‑‑ the national people because we want them to have, you know ‑‑ we want them to help us. ACL has been on everyone of our calls since the storm hit, every single one. Aaron has been on them from ACL, who is new to ACL. He's phenomenal. Veronica is our new point at ACL for our state. She's been on almost everyone of the calls. So they understand what is happening. So has our DSE. We invite everybody. These are the people that we are going to count on ‑‑ what if we need an extension? They need to know that there's a CIL that the building has been destroyed, and they also need to hear from that CIL what they're doing and they're able to do that on this daily call. We try to provide real solutions. Today, one of our CILs asked for an extension for their PPR because of the fact there's no building and they've lost so much. But there are processes that you can put in place, whether it's ‑‑ for us, we reads everything up because of the water. For us, it's getting the computers on the desk and covering them in plastic, making sure that another CIL would be able to assist in calls, having important information that you need on a thumb drive. These are things that our CILs do to prepare for a storm. Making sure that there's a chain that they can call for their staff so that there's a game plan and check‑in with the staff. It would be different, clearly, for a fire if you were preparing and it would be different for a tornado. I don't know that you would put everything on top of the desk. I think you'll probably put things the under the desk. It's for you to decide. There's to right or wrong with, and you would be able to understand that. But then what did FILC do to prepare? That's the state independent living council. We lose contacts, and we lose cell phone towers. You're not calling anyone. The towers are down. Still have towers down. You can call someone but it takes time. We have five communications that I created. We sent all the CIL Executive Directors their cell phone numbers. We have satellite phones that we can activate pretty quick. They all have new SIM in it and we activate them that way if there's a storm, it allows it to be activated for two months. The satellite phones have different ways of charging so we have different batteries to support what is in the communication boxes. We have some (indiscernible) in there and everything has been laminated and covered in plastic. We sent stuff to hurricane Michael. Some of the CILs are operating under a tent and everything got wet or blew away. They were of no use. We have communications boxes in a point. If a storm is coming to a specific area and maybe Miami needs to have that communication box, then we'll have the closest communication box sent to Miami so that they would have it. So they're kind of expensive but we track the inventory, but we activated the satellite phone for Ft. Myers, and we were able to talk to the people that were in that area when there wasn't really good cell phone coverage and in areas where there's no coverage at all. So that was what we did, and then we host those calls and then we put information in those emails to everyone every morning. So like 7:00 in the morning, I send out an email. It has all the updated information, gas stations that are open that are provided to us by the state, where cell phone towers, portable ones, are being deployed. For the very first time, we actually were told that if we could not find one of our consumers or we feared for one of those consumers, we had a direct access to put in a mission for the search and rescue team to go find our consumer, and we've never had that but that's because we're in the EOC. Again, I'm not sitting at a table in the EOC every day but I can go into the EOC at different times in the day, and then I connect with the people that we need to connect. They did not want a Katrina and this was a Katrina type of event. This was a water event. That was the problem. Germán.

>> GERMÁN: Thank you, Beth. We did receive feedback that this is such valuable information. It would have been helpful if a PowerPoint would have accompanied this. We do apologize. The preparedness and allow didn't allow us for time but we will do what we can to put addition materials out if possible. Don't hesitate to reach out directly to us for questions. We'll be happy to simulate all that we have. Beth, a question came a little bit about from Sarah. You mentioned that you were in the emergency management office. That's something we are working and exploring in New Mexico after the peak canyon wildfire, the largest in New Mexico's history. What's the process of getting you established at the emergency management office or you mentioned EOC, emergency operations center. How did you go about this? It would be a helpful tool to learn to hear more.

>> BETH: We did that by inviting our partners, by inviting the people that were in the EOC, like the mass care people, to our daily calls to help us problem solve. So they were getting inundated with DME requests and inundated with challenges that they had not ever thought of, like communication and interpreters and just the entire ‑‑ what the CILs do, the whole wraparound services. And so we ‑‑ you have to be willing to invite them in, and you have to be willing to show that you're a partner. When we have ‑‑ everyone is invited. Not every CIL participates on our daily calls. I don't care whether they participate. We provide and then you become relevant. So this is work. I am definitely in a different ‑‑ there's not a script for this. So be relevant and the CILs, you know, bring them to the table. I'm telling you for the first time in our history, we're able to ‑‑ Salvation Army gets money and participates and they're reimbursed and gets part of the funds that are created here in volunteer Florida. In other places, the governor creates funds to go out to the community. It's always Salvation Army, some of the feeding programs, and then we're asking questions "why not? Why not us? Why not our CILs? " This is where having a national partner is a big deal. For right now ‑‑ I do apologize. I have things on slides but because we're in the middle of a hurricane, I couldn't finish it. But really this is where you have someone like Germán or Shaylin or Macy say "have you thought about this? " Sometimes I go mother them because my brain is full and I can't, but I've learned to listen. And so they kind of tee it up a little bit for you, and you're able to then go and say, yeah, why aren't we getting this? Why aren't we ‑‑ our CILs are out there driving all over and they're not able to have ‑‑ be reimbursed in the same capacity as some of the other state agencies or providers, and I filled out an MOU and told our story. We were accepted. So I don't know what that means for us yet, but I hope it means that the CILs can be ‑‑ the impacted CILs can be reimbursed for what they're doing because its above and beyond. Yeah, it is transition, but are they ‑‑ are we paid for bringing gasoline into a center that has lost everything so that we can generate ‑‑ so we can use the generators so we can charge durable medical equipment so we can prevent institutionalization? That's not what we're supposed is to be doing, is delivering gasoline; however, some of our CILs do that. That happened in hurricane Michael because gas is gone. You're not getting anything. Then we have to decide ‑‑ if the CILs are navigating that, we need to have some type of documentation that says if there's a curfew, we're age to check on consumers. We got that. We're getting gas cards this week for the CIL that will are traveling two and a half hours into rural areas. We've never been able to get that. In order to be at the table, you have to work, work, work every disaster. What's going to happen is you're going to benefit ‑‑ and I'm trying to document with Germán and Shaylin's help, Marcy's help, document what we do in order ‑‑ so it's easier for someone else next time around, and that's what we're doing because there's a process. You have to be able to ‑‑ I really don't feel like doing daily calls right now. I'm tired, but if I don't do it, then guess what? Something else happens. It's great to get support from other states the, but sometimes the support comes in and now they have marginalized the work of the CILs. That's when you have to say, hey, we provide that service and we're open and doing that service. We don't need you to pay another entity to come in from another state to do our job. These are our people, our consumers. So you have to be able to manage the gate, so to speak, so that you're able to say, no, we appreciate your donation. If you want to send durable medical equipment to the CILs, go for it. But you're not going to be reimbursed at our expense when we're not getting any money and delivering this (indiscernible). I say "we". I mean our CILs. I'm not doing activity. It's for communication. When the CILs see that you have their backs and bringing them opportunity and making their job easier, like they all got ‑‑ impacted CILs got $2,000 from Walmart. That came from the EOC to do the work that they need to do. That's a win. Getting any funding for them, that's a win. Getting their ‑‑ and that means we have to collect messages. We have to collect stories. That's the hard part and that's where I screwed up totally in hurricane Michael. Marcy kept saying to Germán and Shaylin, are you documents? I mean, yeah. I'm doing the very best I can, but really it's not even ‑‑ it's not ‑‑ it's not funny. You have to document it or you just did all that work and nobody even knows or cares. And the people that are getting all the credit are those giant agencies that get all the money. Meanwhile, boots on the ground, our CILs, are marginalized. So your job is to make sure your CILs are not marginalized in your state by elevating the work that they do. You have to know what they do before you do that, and we don't ‑‑ I don't say they'll do anything. We talk every day about what we can do. So you have to, like provide that support and respect and communications and sometimes you have to provide workarounds with other CILs, but it doesn't matter. We do that. Even has their attachment area. Everyone is protective of their counties; however, during a storm, we work like a team, and it's kind of how it has to be. So hopefully I'll have something out of this that will be useful for people.

>> GERMÁN: This is Germán. Thank you, Beth. Seeing some hearts and things in the chats. Both has mentioned MOU. This is an approach you find. Alyssa put in the chat ail link titled emergency relocation tool kit developed by (indiscernible). A number of national and CILs disability organizations are part of that support (indiscernible) during disasters, primarily. You will find ‑‑ Beth has talked about reimbursement and as CILs how are you going to, technically, pay for the staff, the time, the equipment, the gas, extra resources for your consumers when no one else is. And FEMA, through ‑‑ even though it has emergency support functions, emergency support measures. And in these measures, you have entities like goodwill, sheltered workshops that qualify, adult daycare centers is to directly provide essential services, as we've been discussing. In 2020 during COVID and reck needing that CILs for doing across the country in response to supply essential services, not only your core activities but going over and beyond, we met with FEMA with the national council on disability through the summer of 2020 in developing what came out as a FEMA addendum for personal assistant services. You will find that in the tool kit. From there, it was recognized that centers for independent living could work with their state, emergency management agency and their county emergency management agency. You will find a memoranda of understanding of how to, ahead of time, collaborate with them. I will put an additional link in the chat. We've mentioned RDIS, or regional disability integration specialist. There are one in every part of the country. You will find a link to email them. If you don't hear back from them in a week or two, feel free to reach out to them. Our colleague in New Mexico encourages you to reach out with your RDIS to help connect with emergency management. With this MOU, we have a success story, as I mentioned, from FEMA PAS. A center from independent living from throughout 2021 and still as there's a nationwide disaster declaration for COVID, a center in Pennsylvania has been able to use this mechanism and the MOU's you will find in the tool kit successfully assisting in relocating people from nursing homes with hoe COVID rates to a hotel, working for reimbursement to cover that hotel, the transporting, a wraparound. So food, water, other essential services that in a hotel room you will not find, PCIS ‑‑ and even if your center for independent living directly doesn't take in these activities now, perhaps you know you don't serve personal assistant services at that agency or fiscal management services. You can still contract that out and you will be the one applying through FEMA. So there are ‑‑ which is how rose to freedom did it. There are ways to go about this. Feel free to explore the tool kit. It will give you the tools you need to show your county and state emergency management this is how we want to collaborate. As Beth has explained, it is helpful having it in your SPIL and understanding what are the services that you do provide now, how can they coincide of essential services in the immediacy, preparing for and response to a disaster and that in the recovery phases you can be involved so the recovery can be accessible. We have centers open. Hundreds of millions of dollars come immediately after. Often times, construction isn't accessible. When you're involved, it can. Beth, do you want to spend time ‑‑ you haven't touched too much on ‑‑ your centers for independent living throughout Florida are helping people right now. It's incredible work. You want to share some of the successes and just ‑‑ maybe not successes but the work happening, which is over and beyond, can give folks ideas. It will be part of after action reports that will help dissemination through APRIL.

>> BETH: Yes. I will. I'm going to say one thing. I ram going to have a constant contact for next ‑‑ that's a check box for me because ‑‑ and for the state. The stories that are coming out are pretty significant. We have ‑‑ our CIL in ‑‑ we've served hot meals for the first time ever. We usually get those boxed things that are not very ‑‑ they don't taste very good, but sometimes that's all you get and that's okay. There's a barbecue, rescue barbecue group that goes around. We have served thousands of our consumers and some of them old, some of them new, hot meals. Not just boxes to go home but hot meals while they're there, checking on them, and thousands of people have received hot meals at our centers. Our centers turn ‑‑ your centers turn into hubs. So if your center is destroyed and you can put a tent up, you put a tent up and everyone comes because they don't know what else to do and this is what happened in Michael and this is what happened here. Over 100 gallons of gasoline was brought into the impact area because there's no gas. And then how do you charge ‑‑ then we set up charging centers. This is something we're going to look into for the future. Charging centers that could be possibly solar charging centers that could be used at our CILs for durable medical equipment, which would allow people not to have to go into a shelter just because they're trying to charge their equipment. That's something that we're talking about. In addition to that, thousands of pieces of durable medical equipment. We have hundreds and hundreds and hundreds all over the state of durable medical equipment going. One thing when you go into an impacted area, you don't go into an impacted area without food, water, DME. You can't. And batteries, things that you know you need. We reached out to my motion to get additional DME that's specific for people. But really what some of the stories have been, you know, that people that are ‑‑ need to get to a shelter or at a shelter and need additional support, that happens. Moms, dads, children, families, and keeping the family together at all cost. Oh, my goodness. That's something that we also learned. Literally some of our shelters are in schools. So those are always the first to close. Then those people go to the next shelter, which is a general pop shelter and then how do we keep everyone together, making sure families that are in the hospital are actually being ‑‑ have some type of communications with people that are, you know, in a shelter or hotel rooms or set up and we try to make sure we secure those. And that was something that we can ‑‑ we also do through the partnership. So, I mean, there's ‑‑ we cannot ‑‑ I'm almost at, really, Germán, just a loss for how many independent things that we've done. The CILs have brought in staff ‑‑ they go into ‑‑ we call him the impacted area. It's not an area you really can stay. There's no hotels or, like ‑‑ we figured out 75 miles away from where the storm hit but then you have to deal with the cities and towns that aren't impacted still hosting national football games and that impacts your hotel space and then how do we have that conversation. We just have it, but there are a lot of challenges that go with that. We first take care of the teams. We have staff that have lost their home in this storm, and it ‑‑ I'm going to tell you ‑‑ I wish we can create something where there was almost trauma care for our CILs because sometimes bringing in volunteers done work out so well because they don't like what they see and people think they want to come in and help, and it ends up being a problem because they're really not helpful because they want to go home. It's a lot of trauma. When you go into a shelter that has, you know, 600 people in it, it doesn't feel super great, but it's a roof and there's food and there's beds and there's ‑‑ sometimes there's no beds. Sometimes it's just sleeping bags. So, you know, it's really important that you take whatever it means to you, whatever it means to your state. It doesn't have to be this but whatever it means, really you could take it to your CILs and reflect on what is ‑‑ our take it to the your state because your state and counties need to work together. Your state and your CILs, they need to work together because there's different solutions and there are some things that I can do for a team that are working 14‑hour days. So we have to kind of pull that together. Calling our consumers is always number one priority right after a storm. And then that is done almost immediately then getting out into the area. At the state level, you can make sure they have access to get out. A lot of times ‑‑ especially, I would imagine in a fire, you couldn't traverse wherever you want to go. You have to permission. There's personal story after personal story and picture after picture, but then it's also devastation and what happens to people that have lost everything. The goal is to keep everybody together, families together, so they don't get separated, stop institutionalization if at all possible and help with that transition, and it is not easy. So you have to kind of be prepared for that.

>> GERMÁN: This is Germán. Thank you, Beth. So much good knowledge there, and Alyssa did share in the chat that we're reminded that the download for this recording will be available later on on the conference website. So many activities and it needs to be taken into a multiprong approach, disaster ‑‑ (no audio).

>> You went on mute, Germán.

>> GERMÁN: Thank you, Alyssa. This is so many activities that you have heard. Thank you, Beth. I made the remind their Alyssa did say the recording will be on the conference website. There's needs to be a multiprong approach from top/bottom, got up to develop a culture of preparedness and be ready to respond. I put a link in the chat to information about two pieces of federal legislation; one, the real emergency access for aging and disability inclusion, otherwise REAADI Act and disaster relief medicate act, DRMA. CILs need support. Beth has been talking about a lot of the work that she's able to do and we compensate and collaborate from the department of inclusive disaster strategies. We are the only national disability led nonprofit, fully focused on people with disabilities before, during, and after disasters. All of our staff have previously worked for centers for independent living. The ready for disaster act is a bipartisan piece of legislation, already in works with senator Casey, who introduces it in the senate and works, who will reintroduce it into the house. REAADI would create disability and disaster training centers and research centers throughout the country, building on the 51% of its staff and services for people with disabilities with a national project of national significance to support the regional training and technical assistance centers. It would also look back at evaluating mismanagement of funds from disasters with a lens of discrimination of people with disabilities and older adults. In disasters, many people also have to evacuate across state lines for an array of reasons. Many of our consumers are people on Medicaid if they receive HCBS, home based services. Healthcare Medicaid services, HBA and chip does not cross over state lines. This is awful and difficult and state to state. It's dangerous in disasters. The RMA would make Medicaid and all Medicaid services follow the person in a disaster across state lines. It would also increase the F map matched to the impact to states two years at 100% and to the states receiving new disaster ‑‑ disabled disaster survivors, those states would be fully supported by HHS and federal medicate at 100% with pre‑emptive and seamless eligible. It would create a pilot program for five states to have a personal assistance response core to have personal assistants ready to have training on disaster and be able to support impacted areas that people themselves are impacted having outside teams ready for personal assistants in the community as the systems today are primarily focused on shelters and other institutions. There's a question on the chat ‑‑ on the Q & A. Many actual name is Kate. This comes from Kate from North Carolina, which gets impacted with natural disasters like tropical storms are but it is usually not enough to have evacuations or shelters. I live independently but use in‑home services to help me throughout the day. I usually rely on natural supports who live an hour and a half away from me when it is a natural disaster emergency. I'm not going to have those natural supports forever. I'm curious if any states have addressed this issue with what happens when there's a emergency so people will use HCBS can still receive services in their homes? Beth, do you have initial ideas?

>> BETH: We are probably not the state to speak on this one. So this is ‑‑ so you're exactly right. This is what happened in Katrina. People ‑‑ this is what happens. People evacuate and they go, and then you're left and all of your services have just evacuated, and so this is the big, huge number one challenge that we're all ‑‑ we've got to think about this. We have to come up with a game plan. We have to support things, legislation, that speaks to this because even though you haven't had that ‑‑ it's North Carolina. I get it. South Carolina. They're areas that aren't prone to ‑‑ there's a lot of flooding in north and South Carolina but it's great that you don't have to deal with that; however, there are solutions to this. We just ‑‑ but it's going to be a national type of discussion because every county is going to operate things a little bit differently. And if we understand that every county is operating things differently, then we needed to address that exact question, like, point on, all by itself because it is all by itself. We are adding new ‑‑ a new SPIL actions in our state plan in order to address that better during a disaster and during the transition period. We have an interesting set‑ up here in Florida, but we are working to address that. But this is a challenge. In some states, a disaster could be very much statewide. Again, it can be a tornado. It could be something else. Don't get stuck on what I'm speaking to because we don't really have, like, really tornados that often here and we don't ‑‑ fires. It can happen but it's not ‑‑ it doesn't raise to the same level. This is where you have to look into your state plan. I'm going to tell you the state plan is as valuable as you want it to be, and that state plan, we put a lot in there, not ‑‑ and two of our goal areas and then we have ‑‑ we had some clean‑up in the other two. But we are adding housing and PCA services and health services in this new SPIL. We're not going to wait for whenever we're supposed to do the new SPIL because we're going to ask for it now. The reason we're going to move forward is because we have to have real solutions right now. You have to assess your own state, look at it, and then put the steps in that are going to allow you to communicate the failures and successes. It's really about taking yourself out of the equation and then putting yourself back into it, if that makes sense, really looking at what would happen if this happened, what ‑‑ you know, what support ‑‑ what really happens here? You just have to kind of self‑reflect on that. I hope that answers ‑‑ you asked the golden nugget of a question that I can give you an answer to that's good enough.

>> GERMÁN: It's difficult. This is Germán. Kay adds in the chat. They know it's the bigger issue. If there's a snowstorm, her personal assistants cannot get to her. Then what? A couple ideas would be in addition, along with home and community base‑services, talking with your coordinator, your case manager, discuss plan A, B, and C. Perhaps having on your individualized service plan ‑‑ ready that if you need services from your agency, that if you're not a direct provider to have an open readiness. If you ask for those things at the moment, it will take time. If you ask the questions ahead of time, it I can be in your ISP. Having a direct number, direct line, if not to your case manager, directly to your home and community based service care organization, correcting with them directly and having a direct number with them. Last year ‑‑ not due to COVID, I was hospitalized due to an emergency with a UTI. They wanted to discharge me to a facility. I had the phone number to my managed care, started calling nonstop. There's no reason why they couldn't discharge me home with the services at home, which they did. So having a number to call that you can trust when you've had these previous conversations is critical. There's been so much information, but it really starts with having a conversation, having conversations at the top level, state, the county, but also with your consumers, introducing the concept of preparedness in peer support groups and learning what where are they most concerned? What are their gaps? We only have a few more minutes left. It's been a packed conversation. If anyone has any lingering questions, please put them in the chat in the next minute. Do reach out to Beth and I. Our information is on the conference website. Take with you, again ‑‑ people with disabilities die two to four times more afternoon than people with disabilities during disasters, including being injured. This comes from the United Nations' understanding from research following the earthquake in 2011 and compensated with research from following hurricane Katrina. This is here, and it's only going to get worse. But by doing things like Beth is doing and we're here to support, involving yourselves and emergency management and developing a preparedness culture will help save lives. Beth, any closing words?

>> BETH: Just the fact that ‑‑ so be part of the solution and that's what I would tell you, not part of the problem. Strategically place yourself as part of the solution because your partners like Germán and Shaylin, they can help you work that problem out because we have to get to a solution. And when those EOC people, who have historically, you know, not opened those doors up, when they see it was party of a team, providing solutions, that they don't even want to deal with, you are going to make a lot of headway. They are wired differently, so it's kind of intense. So be able to come in with calm, got it, handle it, because your CILs are already doing the work. They're already doing the work. So why don't you just let them do the work and you just tell the story. So that's all I have and that you, Germán and Shaylin, for your ongoing support.

>> THE MODERATOR: Thank you, Germán and thank you, both. That was important and useful information. I appreciate that. If all of you would take the time to complete the evaluation when this webinar closes, that lets us now how we can keep providing training to you that you find most helpful. Thank you for joining us. We look forward to having you join our next session, which will begin at 3:30 eastern time. Thanks, everyone.