

REALTIME TEXT FILE

DISABILITY COMMUNITY PLANNING GROUP WEBINAR

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Deanna Baker, RMR, CRC

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>> We're going to go ahead and get started. I am happy to welcome Dr. Tony Delisle. He is Executive Director for the Center of Independent Living of North Central Florida as well as assistant professor in the Department of Health Education Behavior at the University of Florida. He has experience leading community-based supported research, focused on working with minority populations including minority community living in poverty, veterans with disabilities, young adults with intellectual disabilities and students diagnosed with learning disabilities.

The emergency preparedness is just in time for hurricane season. Thank you, Tony, for joining us.

>> Thank you for having me. It's a pleasure to be here to present at your webinar. I will go ahead and get started. We have on tap today is --

[Phone ringing]

>> Sorry about that. What I'll be covering in this presentation is just a brief overview of our center for independent living of north central Florida and independent living network. The broader network that we have disasters and disabilities just a quick overview of that. The factors that compromise the health, safety and independence of people with disabilities. As well as common access and functional needs, independent living network and our efforts to meet those needs in just a quick summary slide.

Just to broadly talk about independent living movement, it started as a social movement in late '50s, early '60s. Ed Roberts was recognized as the founder for the independent living movement. He was trying to go to Berkeley and San Francisco and at the time when they didn't have disability resource centers or policies that would allow people to get into post-secondary institutions. He advocated for his entry into that university and the needs and accommodations that he was desiring so that he can go on to live independently. And this as many social movements has since then morphed and combined and juxtapose itself with other social movements and of that time, in the '60s civil rights movement was occurring and the independent living movement and to this day has utilized some of the strategies that were employed during the civil rights movement. It led to in the early '70s the deinstitutionalization movement of disability. So the deinstitutionalization of disability is largely credited with the independent living movement as well as in the '80s, I don't have this on the slide, a movement that was happening certainly in our country the private

market and capitalism, the consumerism really took off during that time and independent living centers to this day refer to people that utilize our services as consumers. And we really focus our services and programs around what their needs are and we look to them to help guide us in the services and programs. The consumerism which is not on here is an important part of it.

In the early '90s the de-medicalization and movement toward social and environmental towards treating people with disabilities at least how we look at people with disabilities, is a movement that we have latched ourselves on to as well. So, I think that is just an important reference to note in terms of independent living movement. When we talk about programs and services regarding independent living that really came about during that deinstitutionalization of disability. In 1973 the Rehabilitation Act was passed by congress and that's what really gave birth to centers for independent living, the national organization has services throughout the country, there's nearly 500 centers for independent living in the United States of America.

And with that has come also break downs at the state level there are Statewide Independent Living Councils, otherwise known as SILCs we have one here in Florida, the Florida Independent Living Council and they work in conjunction with centers for independent living acting as oversight and support function, supporting the infrastructure needs of centers for independent living. So they're like a sister organization and every state has a State Independent Living Council Florida being ours, is known as Florida Independent Living, if I start saying FILC you'll know. There is a lot of alphabet soup in case I start going toward the acronyms.

But, we have a statewide center for independent living so there's a logo on the side there that is a Florida Association for Centers for Independent Living. And the Florida Association for Centers for Independent Living, otherwise known as FACIL, is a statewide membership organization so every center for independent living in the state of Florida is offered the opportunity to join the Florida association for centers for independent living. And we have nearly 100% membership in that. The next slide I'll show you how many centers we have throughout the state of Florida that comprise the membership of FACIL. National agencies affiliated with the centers for independent living at the federal level, centers for independent living are housed in the Department of Health and Human Services. The biggest agency in our federal government that's in health care. Within the Department of Health and Human Services, we reside in administration for community living, at the national level as well. We have a membership organization known as the national council for independent living. All these organizations are going to become -- it's relevant and very important to maintain to emergency management when we talk about the independent living network. At the state level here, we receive lot of support and funding through the vocational rehabilitation. They're within the Department of Education.

In the state level there are 15 centers for independent living throughout the state of Florida. On this slide here you see each of the different centers broke up by geographic region. The 67 counties that are served throughout the state of Florida. The Center for Independent Living of North Central Florida has a catchment area of 126 counties where the gold in the north central -- 16 counties where the gold is. Each of the different color configurations will show you the different centers for independent living and areas respectively throughout the state. It's important to note, I think, that we have the largest geographic catchment area within the state. Within that catchment area as all centers for independent living, our services are free to the consumers that we provide these services towards. Again like I alluded to earlier, we are consumer driven so very important for us to know the people that we serve. To know what their needs are and to create and offer the programs that align with their need. We are very much of a community-based organization

in that sense.

We serve all disabilities, we serve all ages. I think that is a very important distinction to note about centers for independent living, that we are -- we take all consumers. Independent living keep people living in their homes. Being part of the deinstitutionalization of disabilities movement, we are focused on trying to make sure that people in institutions that we transition this or divert them from going in if they're not in one now.

So, for example, just a living facilities or nursing homes we try to prevent people from going into them. If it is at all possible.

We recognize that the facilities play an important role and coordinated health care system but if it can be prevented at all possible and by services or programs we play a role in that.

All officers for independent living do five core services. These would include independent living skills. Many people refer to them as activities of daily living. We provide individual and systemic advocacy, peer support so we believe in people with disabilities supporting people with disabilities. Transitions, again transitioning out of institutional care facilities or diverting them in the first place is very important. Transitions as of late is also come to be defined as transitioning young youth with disabilities from high school to post-secondary education or employment or whatever life after high school would look like for people with disabilities. Transition is also encompassing that part of transition.

And information and referral services, so if we don't provide the programs and services for people with disabilities that need them we want to make sure that we do. All centers for independent living are required to do these five core services where centers for independent living can look differently. Supplemental programs and services that are provided by each of the centers, again, we really try to get to know our population that we're serving and try to know what their needs are and so creates a program that are aligned with meeting those needs. Each of those programs may look different for each of the different centers, depending on the needs of the community that they serve. In relation to our center, we have high school hi-tech program, we're in five counties, trying to make sure people with disabilities graduate are successful in post high school. We provide paratransit services for Marion and other counties. Employment services where we're trying to find people with disabilities jobs and sustainable employment, we provide sign planning interpreting services, we have a wheelchair ramp building program. We do distribute some durable medical equipment and we do a lot of disability awareness type trainings within the community.

As of late, since I've been here as director for a little over four years, we have really grown in working with disaster preparedness, emergency management with people with disabilities. And this takes us to the presentation that we have here today to talk about some of the activities that we have been doing with and partnering with the Florida Department of Health and University of Florida. We've done some really accident work and progress in this direction and the presentation here will encompass some of those efforts.

And before I get into it I think it's really important to note what is out there in terms of our responsibilities. In meeting the needs of people with disabilities in disasters. The National Council on Disability had a report that came out in 2019 in which it does speak to this and talking about one of the most important roles of our government is make sure that they protect our citizens from harm. This obviously includes emergency disaster, help to make sure that people are prepared. Local governments and emergency preparedness and response programs are need to be accessible for people with disability. All people. Particularly with people with disabilities can be a challenge, this is a critical part of the responsibility. Making these programs accessible for people is also a requirement for the Americans with Disabilities Act. So, what I'm about to talk about here, it's important

because it's a good thing to do in terms of protecting safety and health of people especially that are vulnerable but this is something that is a requirement and perhaps one of the most important functions of our government is to keep people safe.

When we talk about disability and disasters, people with disabilities are recognized as the most vulnerable population during disasters.

That would include people with disabilities and to be less prepared for disaster not having a plan, social support or supplies that are needed ahead of the disasters. During the response of a disaster as the disaster is happening, tend to be more vulnerable than recovering from disasters. Often have factors that contribute to their challenges that are related to recovering after the disasters. We're going to talk more about disasters related to hurricanes where in Florida many of our efforts have been directed toward hurricane response. But thousands of families with disabilities are impacted and often dislocated from their homes when hurricanes hit. This really strikes to the core of independent living again we're trying to keep people in their homes and in their communities. These national disasters these hurricanes really pose a big threat to the core of what we're all about in terms of keeping people in the community in their homes. As many of you probably know, people with disabilities are often dislocated from their homes, it happens at a large level and something that we're very committed toward addressing because this goes towards our mission of independent living.

Between the recent hurricanes that have hit, Harvey, Irma and Maria is estimated, those three alone have impacted 47 million people. That is nearly one out of four of them, 12 million people have disabilities. So that's a large percentage of our population being impacted by these storms, certainly a large percent with disabilities.

Hurricane Michael dislocated a little over 30,000 households. 30,000 people believe one in four of those households had a disability. When I say dislocated, people that do not have a home any more. And Hurricane Michael was a very devastating one because it happens in a rural area and many people have been dislocated throughout the state. But this location that is caused by all these different hurricanes, Irma, Maria, everything really go towards again what we're trying to prevent people getting institutionalized.

A little data that we do have on institutionalization and numbers can be shown in this line graph here. Hurricane Irma and as it made landfall when we look at the numbers, people that were in nursing home care -- nursing home care facilities, when Hurricane Irma hit and then we see the spike immediately after it hit. Then downward in terms much getting it back to where it was, pre-hurricane is very reflective of other hurricane land falls as well as Hurricane Harvey which struck Texas. Again, pre-hurricane then a very quick spike in the number of people that are in nursing homes afterwards. We see a high rise of institutionalization afterwards. They weren't only a place for nursing home care after a disaster. We talk about youth that might be dislocated, we could be talking about children and family services, hospitals, there's a lot of different other facilities out there that would swell up after a hurricane in terms of institutionalized care. People with disabilities going into them. It doesn't capture all the different kinds of institutionalizations that can happen after a disaster strikes. This again goes to the core of what we are really trying to mitigate, in terms of making sure that people are not institutionalized to whatever extent possible. Disasters provide -- present a very big threat in that direction.

When we look at economic costs of disasters, we see the large majority of costs come from nearly over half from tropical hurricanes or tropical storms that tend to hit, severe weather, when we parse that out certainly a big factor. Look at weather-related impacts of disasters, economically, the majority of it does come from the weather.

Now I'm going into the slides that have to do with what before these disasters hit people with disabilities are particularly vulnerable population. Pre-disaster, people are already

predisposed to be in a population that we need to really be paying attention to and explains why we're vulnerable.

This slide comes from the Robert Wood Johnson Foundation this graphic higher to explain why people with disabilities before disasters tend to be a vulnerable population. We look in terms of health inequities, health disparities in people with disabilities. The data is very clear, data in Florida department on disability. University of Florida puts out a report that really draws our attention here in the state of Florida to the disparities. When you look at the top two cells here in the report show that the chronic disease prevalence in people with disabilities is multi-duplicative in people with disabilities when we look at coronary heart disease, three to four times greater with people with disabilities. People with disabilities tend to have twice the rate of cancers, aggregate as people without disabilities. The rate of diabetes is twice as much. Respiratory diseases tend to be depending on the respiratory disease, 7-11 times greater than people with disabilities. Pre-storm, when we have that rate disparities within our population, this makes this a particularly vulnerable population before the storm strikes. The evidence is very clear with that.

When you look at the factors that contribute to those health disparities, Robert Wood Johnson Foundation, this comes from the county health, based on epidemiological data from the national surveillance. People with disabilities when you look at health behaviors, tend to get less physical activity, depending on the disability, alcohol and drug use might be higher. Access to quality health care tends to be lower, health literacy. But social determinants of health being impactful, less likely to graduate high school, higher unemployment rate, lower income which can be very important factor. In families with social supports, pre-disaster as well in being able to meet some of the needs that are there before, during and after disasters, certainly the environment is very big factor. Pre-disaster in the health disparities that we see are one of the factors that make us particularly vulnerable.

Another one is just social and environmental context which disability exists in our culture. We obviously know being part of this group that the social, cultural normative attitudes towards people with disabilities, some of the stigma that is there the oppression, neglect, stereotypes, just that social attitude certainly is a factor. We have the built environment that can be difficult to overcome especially talk about access in functional needs. How society very much views disability and certainly the environmental barriers that are there are problematic when we are addressing access to functional needs. We'll talk about how that plays out.

Accessing our community, people with disabilities tend to be tough to reach population, organizations like ourselves are community-based organizations that work with people with disabilities. Thankfully have the ability to reach our population. So that's very important thing when we talk about community of people who have disabilities, we want to be working with organizations that actually reach them in terms of emergency management, there's been eagerness in people that work in emergency management to want to access community. And coming from where they come from responding to emergencies they don't want to just meet people with disabilities in emergencies, big emphasis trying to meet people with disabilities before the emergencies strike or disaster strikes. There's a very important way -- movement now to try to meet people with disabilities and try to connect all these different communities together, emergency management and people with disabilities and community-based organizations that serve them and we'll talk more about that.

But one of the things that compromise the health and independence and safety of people is after the disaster strikes. There's a lot of different services that are out there in terms of long-term recovery. How do we connect people that are in clinical coordinated

health care systems and emergency management response. To these different types of organizations there might be providing social supports and services that are needed after a disaster strikes. And it can be a very complex system that is out there and coordinating the different services and agencies that are out there that can assist people with disabilities post disaster, can be problematic. Navigating these complex systems is very difficult so finding that bridge organization that can be helpful often find those community-based organizations that address a lot of those determinants of health post disaster are very important. Right now pre-disaster understanding these systems can be one of the important factors that is there.

Common access and functional needs that we see. That are in Florida and other places. Will be some of the things that we're covering in this section of the presentation.

It's important to know what access and functional needs means. There's typically five dimension, that comprises access and functional needs. We talk about access and functional needs is the graphic below there shows that this is for all people. All people can be presented with difficulties in accessing services and programs and functions, that they may have and so this is something that we really want to address with all people not just people with disabilities. People with disabilities tend to be a subset but obviously if we're meeting access and functional needs of people with disabilities then that makes it universally access for all people not just to have disabilities but for all people that may need some assistance. So, for example, people before a storm or disaster strikes who may not have mobility or issues, because of the disaster may then encumber a disability, maybe they didn't need wheelchair access to get into special needs shelter but post disaster they may need it or have difficulty walking. A lot of the access of functional needs that we need to focus on aren't just for people with disabilities but certainly will help people, all people make it universally accessible.

These five components are transportation, communication, maintaining health, independence and services, support and self-determination. So this is what really the five components of access and functional needs encompass.

We talk about transportation. These are very important question to think about when people who have transportation needs, how are they supposed to evacuate, how are they supposed to get the special needs shelters. We have a paratransit program that we offer again like in two different counties. People have to come to us to see if they're eligible for these paratransit services. This is one of our most utilized services that we offer here. Transportation is an issue that cuts across all the different programs that we have here and operate here at the center. A very common need for people with disabilities who may not be able to have the function, for example, me, I have a low vision disability. I do not meted vision requirements that are needed to acquire a driver's license. Some people may have mobility issues, economic issues, again people with disabilities tend to be in poverty or are challenged in terms of socioeconomic status can't afford to have their own transportation and often rely on public transportation. Here in the county our paratransit provider is something that is called upon by the Department of Health to evacuate people into shelters, so they are a part of our system in terms of transportation to ensure people with disabilities can get to shelters. But oftentimes as most people are reliant upon social supports when people are needing to evacuate, that's where transportation meeting the needs of transportation for people with disabilities often fall on social support that people have and if you don't have social support, public transit becomes a big factor in terms of people with disabilities are able to evacuate or in need of going to shelters. On of the aspects that probably gets one of the most attention to provision of sign language interpreters before, during and after disasters would hit. Another one the that tends to be close second ability to effectively communicate. Again, when we talk about

communications, we got to emphasize the word effectively. Communicate with people, people with disabilities not just people with disabilities that might have needing of sign language or auditory but when we think about intellectual or mental health or any kind of other disabilities that would require people to have social etiquette or sensitivity to communicate with people that might have different types of ways of communicating based on their disability. That is also a very important one. We get a lot of requests to help emergency management professionals and/or community county health department staff who are staffing shelters to get educated on how to effectively communicate with people with disabilities, social etiquette. That accompanies that.

When we talk about provision of sign language interpreters, that can happen before, during and after the event. Here on the slide there's often public information that is shared by government officials about the incoming storm or hurricane is very important that sign language interpreters are included as required in those public announcements, especially if it's being televised make sure that that sign language interpreter in the bottom is included in there.

There's a movement called stop the crop, often the sign language interpreter tends to be cropped off of the screen or is really kind of not seen in a way that makes it effective for people who are needing a sign language interpreter to communicate. There's also closed captioning that can be provided in terms of CART services.

Video remote interpreting, isn't typically what is the most desirable in terms of the population we serve who are deaf but sometimes it becomes a very important tool to be utilized during disasters especially the shelters if they're able to have power, that might have to be something that we would go to, not the optimal but certainly can be utilized as a backup.

Ideally we'd have sign language interpreters staffed at the shelters, public information announcements that are made. Even emergency operation centers are requesting interpreting services.

Effective communication when it comes to sheltering. Access and functional needs that are there. Very important. This tends to be -- has been a very big and important focus of ensuring that we have adequate communication when people enter into a shelter. So you think about all the different shelters that are open during the disasters, there's quite a few. And how do we ensure that each one of them has the type of means and resources necessary in order to meet the communication needs of people that are entering the shelters. If they're deaf, they're blind, if they have cognitive or intellectual disabilities, there's a lot that needs to be put in place ahead of time to ensure that the facilities are appropriately staffed and equipped to meet the communication needs of people with disabilities. Especially on a statewide scale when many shelters are active.

Communicating during disasters, one of the things that I wanted to talk about was something that we've seen in working with the emergency operation center. When a disaster hits and during the response phase, shortly after, there can be a lot of communication that's word of mouth. And understanding which is factual and what is not factual can be a very important thing to really kind of find out. We're learning as we were working with the state emergency operation center, we would hear some access and functional needs, we were able to put in to the state's emergency operation center a mission to where they would actually be able to send emergency management professional and personnel to go run down that mission to find out indeed if the information that we were getting had to do with access and functional needs or not.

Again, when disasters hit there can a lot of miscommunication and misinformation that are happening, we would consider it like almost like the fog of war as it is happening. And there's not a lot of communications on the ground, especially with Hurricane Michael didn't

have cell coverage in that area. And understanding exactly what was going on was very problematic, we were getting in a lot of information from a large variety of different resources about people, perhaps not having access and functional needs met. And it was great to have the link in with the state's operational center they could actually put in a mission to have emergency management professionals go to wherever it was we were sharing information about who might have access to functional needs and able to coordinate that.

Emergency management professionals and volunteers are communicating to people with disabilities. As many of us know on this call here, there's certain etiquette, certain ways of communicating with people with disabilities, certain words to use to not use, people first terminology. How we might communicate to somebody who is blind, how we might communicate with someone who some has intellectual or mental health disabilities. And being able to do that is very important. Many time emergency management professionals are people that are staffing our shelters, may not have a lot of interaction or experience with people with disabilities. So, one of the things that they have been seeking a lot from us and from others is how do we effectively communicate, what is the social etiquette, how do I communicate information in a language that people can understand and act on.

There's a big issue with effective communication, when shelters do get activated you'll get -- whether it's a special needs shelter, whether it is general population shelter, you are going to have the general public within earshot of one another. When you're communicating with people and there's different staff in there, there's different agencies that are in there, that are trying to meet access and functional needs of people, confidentiality and sharing of information is still in play. And that can be very difficult when you're not in a clinical setting any more. You're in a school and there are lots of people in a small state and there's different agencies there that are trying to meet needs. And sharing of information about people and HIPAA and other types of laws out there and agencies environment to make sure that we are keeping people's identity, their health needs, their health status is still in play and can be very difficult when we're dealing with the emergencies and situations where -- that are not ideal necessarily. That's something that obviously that needs to be something that is thought about and planned for and trained for.

When we talk about independence and maintaining health again two other components of action says and functional needs. Some of the issue area, common issue areas that we've seen are provision of durable medical equipment or adaptive equipment. This may be for people who have disabilities who had to either evacuate or shelter, and weren't able to bring it with them because maybe they had to do it quickly or didn't prepare ahead of time didn't have it with them. If they are now coming to a shelter and they are in need certain mobility equipment or assistive devices, does the shelter have it, are they able to get it?

If people who before the disaster didn't have a disability or mobility need but now because.

Disaster might need crutches or wheelchair or anything else like that and they have had to evacuate the shelter is there equipment on hand. People that are electronically dependent, that might have those devices or needs of wheelchair or anything that has power, do they have enough power are their batteries charged up ahead of time when they're going to a shelter. Does the shelter have the type of outlets that are there to charge? Sometimes the outlets that are medical, especially those that have a lot of electrical needs, really want to make sure that the shelters that they're going toward have that kind of electrical access to make sure that they have their needs met.

Some of the medical equipment that's out there requires a lot of voltage and certain

outlets that are needed to charge those medical devices may only be accessible at certain shelters. Knowing those medical need shelters ahead of time that would have the ability to meet the voltage needs is very important.

Oftentimes people who are reliant on personal care attendants or just home caregivers, not even talking about people that are needed 24/7 but maybe intermittently are often separated from one another. If you have somebody with a disability that is either evacuating or going to a shelter and now do not have a personal care attendant or home care giver that might have been giving them some support, now what are they supposed to do?

How are they supposed to function?

That's something that shelters and being prepared after the disaster is important. And people with their service animals as well, is an issue that needs to be paid attention to and very common access and functional needs of people with disabilities.

Often when we give our trainings to people who staff shelters, one of the things that they will ask about is service animals. Because they try to separate pet sheltering from sheltering the general population. But if you have and require a service animal due to a disability, you're allowed to bring your service animal into a general population shelter. Or a special needs shelter or any shelter. So that's like considered durable medical equipment. So it's important for shelter workers to know the two questions that they're allowed to ask. A lot of them will ask us because they don't know what questions that they're allowed to ask. Make sure that people are coming into the shelter that it's a service animal, not a comfort or emotional support animal, those would not qualify as service animal to be allowed in to the shelter, they would need to go to designated pet shelter. As many of you know on this call, you are allowed to ask if the service animal is required because of a disability. And if so, what work has it been trained or tasked to do to perform. Obviously you're not allowed to ask the type of disability or anything else outside of these two questions to discern if an animal is in fact a service animal when entering into a shelter.

When we talk about independence and maintaining health, right now there's a lot of focus on trying to ensure that people that have intellectual or mental health needs are also being met when they're sheltering and maintaining their health and independence is very important. As many of you know, people with autism can have difficulties with stimulus and are challenged with certain social and environmental triggers, that can be very difficult for them. This can include also people with post-traumatic stress disorders or their mental health issues. Certainly sheltering and type of environment that you have in shelters where there's a lot of people, a lot of noise, a lot of stimulus a lot of stress can be the exact worst environment for somebody who has these types of disabilities to be. Working with Bryan and others who are very interested and eager to really solve this issue, seeing how can we make our shelters more autistic friendly. Or sensitive to people who have -- may have mental health issues or needs or post-traumatic stress or any of these other kind of things. How can we make these environments easier to be able to maintain their health, their mental health and their independence as they're coming in there? There's a big push to address this issue that are in there. Trauma informed care and medications sends to be something that needs to be paid attention to in terms of maintaining people's health. Again, disasters, sheltering, very stressful, very traumatic for the people that are having to be sheltered. So as we deliver care, as we provide sheltering for people, understanding that for anyone with or without disabilities can be very traumatic. So that needs to be something that's really -- there's a lot of education now that we're delivering that has trauma informed care baked into it. Then medications, and alcohol, tobacco and other drug use, people have substance abuse or use issues and now during the disaster they're in a

shelter where they don't have access to that and may be going through some withdrawal. So maintaining their health as they go through withdrawal in a very tough situation and environmental situation, social situation, people that might have prescribed medications that they might not have either brought with them or weren't allowed to get before the disaster because there are certain rules and regulations about dispensary of medication and weren't able to get enough medications that they're going to need after the disaster is a very important thing to pay attention to.

We talk about services, support and self-determination, that other component of common access and functional needs. The discharge planning process, after people are leaving the shelters, lot of times staff that are there at the shelters and their knowledge of disabilities may be good or may not be. A lot of times people again that are staffing these shelters whether they're general population shelter might not have a lot of experience in working with people with disabilities. And they are here now discharging them, what is the plan. We learned in Hurricane Florence a lot of times people that were discharging people from the shelters were transporting them, didn't really have in mind that preventing institutionalization was very important factor. What are the transportation barriers that people might be facing if the shelters are closing? How do we track people once they leave shelters? Once they leave the shelter, where are they going?

This is a very important question to understand because aligning the program and services are very important. At least when they're in the shelters, assessing their access and functional needs are very important thing. There's multi-agency assessment teams that have been recently deployed, we've been a part of and trying to help understand what some of the needs are within the shelters, because then you can really work to meet their needs. Not just within the shelters but shortly after leaving the shelter and navigating the resources that they're going to have to have in place to make sure that they have the social support services for self-determination after the disaster has hit. Navigating those resources, applying for FEMA and other public assistance might be eligible for. Portability of their health insurance, especially if they're dislocated and going across county lines we found to be very problematic and issues.

Long-term recovery organizations, after disasters hit, there's a lot of federal funding that will be provided to organizations to address long-term recovery needs, such as housing, food and relocation. Those community-based organizations that are part of those long-term recovery organizations are very important pieces of that operation. Make sure that that is taken care of.

Some other access and functional needs that are often -- I alluded to this earlier, access to prescription medications. I've had a lot of people tell me that they knew hurricane was coming, they were preparing to evacuate but pharmacy and rules regulating especially opioid medications even if prescribed prevent pharmacies from distributing these medications. This might be when they are needing maybe to go without month or two because they're evacuating or they might not have access to the pharmacy that they're going to so access for prescription medications this they needed, are very problematic, these are people that are needing them. Meeting the needs of people with disabilities with mental health issues like I said before. Sheltering for the homeless or precariously housed. When shelters are closing and people that are in those shelters, we saw this after Hurricane Michael when the numbers started getting very low, what do you do with people who before the storm are homeless or may have been staying with people, now have been separated from the people that they were staying with? And now are in a situation where they don't have anywhere to go. And the shelters are looking to close, to reopen to start school. What are we going to do with this population here before the shelter? It is an issue that people are trying to get their head around, after Hurricane Michael again with the

devastation with that hurricane, lot of people didn't have anywhere to go. It was very tough.

Again, Medicare and health insurance portability if people are dislocated, how does that work out. And access to residence after a storm is hit, if their residence has been condemned and people are needing to get back in there for durable medical equipment or medication or even supposed to be there when FEMA is coming by to assess, to maybe qualify people that they have been dislocated has been a big issue as well.

So I'm going to talk now, this portion of the presentation addressing these common access and functional needs that are out there or what are we doing about it to address some of these. The independent living network. I talked about our Florida Independent Living Council, our statewide organization, Centers for Independent Living, the Florida Association for Independent Living. As long as our National Council on Independent Living they have subcommittee and independent living has been very active and great partners with us as we've been trying to meet access of functional needs. Our administration with the independent living as well, paying a lot of attention to us and watching us, looking to support us and learning as we go along about ways to be able to do that, recognizing that this is a very important part of the independent living movement.

One of the biggest ways again, you saw this graphic earlier I just want to really underscore this, that the independent living movement has been a very key partner in this. That we're really helping to bridge emergency management professionals with the community that we serve. We find that one of the biggest roles that we can do is to really help to foster this collaboration. Reaching people, garnering their trust, educating people on how to communicate with people, doing a lot of the crosswalk in terms of the jargon that is used in merge see management profession. How we use the jargon that we use in our profession, lot of the social etiquette and effective communication that is needed with this community. Being that organization that can really link these three different communities together has been a very important role that we've been able to fill.

Before the disasters hit, during blue skies as it's called in emergency and proceed incoming world is very important. Our partnerships with county health department at the county level, every county has emergency support function, each of those have boards they meet regularly and participate on those boards is very important. Every county also has an emergency operation center and it's very important that we reach out to the county health departments that are in our catchment area, understand our ESF8 groups. Be a member of them, one of our staff here actively sits on many of the ESF8 groups that meet regularly just to know the different emergency operation center personnel that are within each of our counties because when a disaster hits, the counties really take the lead on meeting the needs of the disasters. So it's very important that centers for independent living and independent living network really knows and networked in ahead of the storm with a local county health department, because they're the ones who are often charged with running the shelters or ESF8 or EOC and charged with meeting the needs of people, access and functional needs when disasters strikes because they take the lead locally when that happens.

We've hosted expos related to disability readiness which I'll talk about later. Participating table top or live trainings with emergency management professionals. We've actually provided people -- we've actually have helped when there's a live training, they will often do live drills, emergency management professionals where they will create a scenario where emergency management professionals have to go in and mitigate a situation, they don't know what they're walking in to, this is something that is predesigned to test the responsiveness of emergency management professionals. Oftentimes they will have people who are victims and playing the role of a victim and acting out whatever trauma might have happened to them in a disaster related to this scenario. What we have

been able to do and other centers throughout the state have been able to do is provide people -- these trainings can, people who are running the trainings we've gotten people with disabilities, real disabilities to go volunteer be a part of these live trainings and so instead of something pretending to be blind or pretending to use a wheelchair or be deaf, these are real people with real disabilities participating in these trainings in the emergency management professionals get to -- part of their training get to work with people with real disabilities in terms of mitigating whatever scenario it is that they have been charged with training.

And often, after the debriefing and the after action of the training reporting more often than not this is area that gets the most attention of focus. It tends to throw most people for a loop where a lot of teachable moments happen and working with the people who have real disabilities. Bryan and others have -- and Independent Living Network has been collaborating a lot ahead of the storms trying to get memorandums of understanding or at least agreements with to make sure that we do have sign language interpreters ahead of time, positioned and staff. To make sure if there's any way that we can get personal care attendants or anyone else ahead of time to volunteer, to say that they're going to be not pocket to be able to do that is huge. Addressing multi-agency information sharing ahead of time also getting those -- like I was saying earlier, ahead of time so that we can share information so that we can meet access and functional needs is very important. During these blue skies, there's a lot of things that we're doing to make sure that before the disaster we can be better positioned when the disaster strikes.

Again, when we focus on independent living and self-reliance, one of the things that we really want to do make sure that people with disabilities ahead of the storms are prepared so sometimes that means if we know that someone has a type of disability, that does need special needs shelter, that we make sure that they are registered ahead of time. They're not registering while the disaster is hitting. That doesn't mean everybody with a disabilities needs a special needs shelter, that is very important conversation to have of exactly who really needs special needs shelter and who does not. Special needs shelters are really meant for people who really need medical service, hospital-almost type care to go to. So, who are these people that are going to need that type of care ahead of the disaster and need to register for these special needs shelters so that is already taken care of ahead of time.

There's a lot of different alert systems that are utilized through, I know that the state -- every county kind of has a different alert system, there's a statewide alert system, they have been getting more aggregated together so there's unified alert system. Making sure that people, all people need to be sure that they're aware and signed up with the local alert system because that can be real-time information that people are needing as a disaster hits.

Obviously people having the supplies that they need ahead of time along with the education is very important. Our center and many centers have provided emergency supply kits, educated people on how to make a plan, give them the skills ahead of time that they will need to make sure that they have the things necessary to respond and recover from disasters.

That is all things and activities that we're working on ahead of the disaster.

As I alluded to in slides earlier we've been doing emergency management expos, we've helped to host five of these so far. In three rural counties, we've also co-hosted with the Center for Independent Living, the Independent Living Resource Utilization Center -- I'm sorry, Center in Jacksonville where we have what we call an expo, it's basically a half day event where we have emergency management professionals of which we advertise to the population of people in the community, people with disabilities that is emergency disaster

preparedness event for you and your caregivers to come to where emergency management professionals are helping to host this event, whether we talk about specific issues related to access and functional needs, emergency management professionals are often part of keynote speaking, panel discussions and we also invite other community-based organizations that do serve people with disabilities to come there and table. Oftentimes we'll have 15-20 different other community based organizations that are at these events that are tabling and becomes very interactive part of our expo where people with disabilities can then learn about other resources that are out there. We're really looking at three different communities coming together for those half-day events. We got the population of people with disabilities who are participants and attendees and their caregivers. But also now we've got the community-based organizations that are there along time emergency management professional. We look at this -- these have been very successful networking events, these aren't standalone often they have follow-up activities. We've been invited to do many different community health department trainings from this because there's been other counties who have sent health department personnel to these events then come back asking us if we can do trainings, this is often fostered relationships between emergency management professionals and other community-based organization, previously weren't working with. Obviously the people with disabilities that are there that are meeting the emergency management professionals face to face and getting to know them, emergency management professionals getting to know the people with disabilities, getting to have the interfacing with them is very important part of that. As well for signing people up with alert systems that are there, this has been a very important piece of what we've been doing during blue skies to make sure that these communities come together for networking and preparedness.

So, once we talk about once the disaster hits, the independent living network has daily interagency calls. So immediately after Irma the day after Irma and day after Michael, and when Dorian was coming, the week before Dorian came, the independent living network activates. And this is driven by the Florida Independent Living Council, where they will host daily calls where many different entities call in to the calls to be able to talk about how we can communicate, coordinate and best position ourselves to meet access and functional needs. You have the Florida Independent Living Council, as well as centers for independent living throughout the state calling in to these. We've had Bryan, access and functional needs coordinator calling in to this, people representing ESF8, FEMA represented on this. Have had some national council on independent living leadership call in to this. We've had partnerships for inclusive disaster strategies, national organization who has phenomenal expertise and insights to respond during this disasters call in to this, Red Cross, Disability Rights Florida. There's a litany of different agencies that call in to this to really coordinate and communicate our efforts to meet access and functional needs.

That has been a very important piece of the pinned dent living network and our ability to communicate. Through our partnerships with the state EOC and through access and functional needs there at the Florida Department of Health, also calling in to the calls that they're hosting as well. There's multi-directional communication that is going on in terms of interagency calling with one another, that's very important.

The Multi-Agency Assessment Teams, MAAST, this was something that we started participating on with Hurricane Michael when the shelters were activated, staying open for a very long time because the level of devastation that happened there. We had mull time agencies coming together to go into the different shelters, I think there was nine of them at the time, where people from the department of child and family services, agencies of people with disabilities, center for independent living was represented, elder affairs, people that were used to working with people with disabilities and at least working with this

population came together in multi-agency teams to go into the shelters to assist on assessing access and functional needs. And once we understood those needs were able to elevate.

Often we were running down a lot of durable medical equipment, getting interpreters, advocating for people, getting information and referral out there. We also were able to have some influence on discharged planning process, again this tends to be very important piece of the puzzle in preventing unnecessary institutionalized care. Working with people who are discharging from the shelters and really making them aware that just because they have a disability doesn't mean they need to go to institutional care facility, that there are alternatives out there.

Again this is underscore importance of the MAAST teams to help assess some of the needs. Elevate those needs to attach and run down those things. That was very important piece that we were able to serve, be a part of, to help in the training of and to help meet some of the needs.

One of the things that we were also able to help out with, that we learned from the people that responded with Hurricane Florence, importance of FEMA assistance. FEMA assistance to a very important part of the recovery process and when people are applying for FEMA assistance, especially if they have a disability, need to make sure that they're filling out the applications appropriately. Sometimes people are there to assist people with disabilities, to apply for FEMA times there's not. What we found out in terms of the FEMA application process for assistance, there was one question on there that if people did not check the right box and had a disability they were denied assistance. We learned from for Hurricane Florence in working with our centers up there and they found out that people with disabilities were not recognizing that question 24 was discerning question asking people if they had a disability or not. As you can see on the question here, again if you have a disability you may have intellectual, mental or literacy type issues, you might easily not check the right box on this question. For me, even as professional I don't see this being necessarily very cut and dry question to be able to ask somebody do you have disability or not. So, what are your needs?

We're working with FEMA, we've been able to provide some information to them, they're working on trying to change this question, make sure that people with disabilities are very well aware that they have -- that they can answer this question right to make sure that they have their needs met. One of the things that we were able to do after Hurricane Michael, learning this is that we were able to really push the word out there to people that were helping people with FEMA assistance for people with disabilities who are applying for FEMA assistance to understand you need to check question to question number 24. You have a disability, access and functional needs, need assistance, have to make sure that do you this appropriately. Participating just in time training make sure that people get assistance they need.

There's a lot of systemic advocacy efforts that the independent living network is supporting at the national level. The READI Act is going through congress, it has senators that are sponsoring this. It's a very important act that can really help prepare people have disabilities and older adults ensuring that they have their access and functional needs met. We've been trying to again work with FEMA on some of the collaborative efforts that are needed after the disaster, getting that question better. Administration for community living that we are a part of at the national level as well is being supportive and working with us to identify how they can best serve as a role to support centers for independent living once disasters strike. The Florida Association for Independent Living. And their legislative agenda has really tried to put on there to be more of an influence at the state level.

When we were working with our legislators up there that they keep in mind that there's a lot of legislation out there that can really be provided that would help to make our supportive people with access and functional needs met.

The state plan for independent living, every state has to do within of these every three years. This year we are drafting our state plan for independent living in conjunction with the Florida Independent Living Council. One of the goal areas that we're put in for our state plan to do better in disaster preparedness and access to functional needs. So this year we're drafting this plan which is really going to direct that resources for Centers for Independent Living for the next three years. And in writing the state plan for independent living, which needs to be approved in June of 2020, we're really putting in a lot of things that access and functional needs are met for all Floridians. This can be something that public comment, people can have influence on to help provide any kind of advice on where people think that our access and functional needs efforts and resources should be directed. Again, addressing we are also work on local issues that are related to disasters.

There is statewide an affordable housing issues that are going on, nearly everywhere in our state as well as nationally. Affordable housing is a major issue when you talk about people with disabilities, affordable and accessible housing is an issue pre-disaster. So when you look at housing market, the housing stock is not there before the disaster then after the disaster when you have tens of thousands of families that do not have a home to go to and depleted housing market, just really exacerbates the affordable housing issue. Then when we have people relocating from Puerto Rico, now perhaps the Bahamas, again we are a unique state that affordable housing issue has whole other different dimension put on to it so it really at a local level to work ahead of time. Home care is a big issue pre-disaster. Making sure that people have type of home care or personal care assistants that they have and they are needing to be independent and living in their homes is an issue. But after the disaster again this issue area to be exacerbated. How do we meet home care and personal care needs of people with disabilities to ensure that they can stay in their homes after the disaster. Even becomes more magnified. When we look at these overarching issues, whether it's housing or home care that are really important issues that we focus on before the disaster they become magnified after the disaster. That is something that really need to focus on, not just locally but nationally.

So, in summary when you really think about some of the issues that are out there, we looked about needing access and functional needs of people with disabilities. The communication, notifying people. Communicating is a very big one. Sheltering, transportation, evacuation, temporary housing. People after the disasters tend to be something especially dislocated transitioning back into the community of people with disabilities have been dislocated have been put into assisted living facility, hospitalized, nursing home, how do we get them back into the community.

Long-term recovery process, there's organizations that are in part of the long-term recovery, this doesn't get a lot of attention. Lot of the media attention after the storm, during the storm and just immediately after the storm look at the damage, media pays a lot of attention to, what doesn't get a lot of media attention is the long-term recovery process. Where are the people now that have been dislocated since Irma and still have not found housing? What about the people from Puerto Rico that are still recovering here in our state from Maria. From Michael.

When we look at national news or local news these people don't get the attention but they are still recovering right now from these disasters. And are needing a lot of the resources that are needing post disaster and getting the resources in terms of long term, if someone has been dislocated from the county they no longer live in the county they lost their job, have to relocate their family to another part of the state, having to relocate to

different schools, to get their way back to bay county is a very long road. Can be very troublesome, particularly if you have a disability. The long-term recovery process is an area that is deep in terms of the needs out there to leverage resources to make sure that people with disabilities are having their needs met during that recovery phase. It's very important, it is ongoing and it certainly is long term. I've done a lot of talking. I don't know how much time we have. Necessarily for questions but I would be happy to entertain any and all questions that might be out there regarding this presentation.

>> Thank you so much, Tony. Anybody have any questions, we'll give it a minute. We're a little bit over on time, just want to make sure that everyone has chance to ask. We might also send out Tony's information, his e-mail and he can answer -- there's Kevin.

>> I put Kevin on there. He's been one of our staff doing a phenomenal job he's been sitting in on lot of the ESF8 groups, opening doors, very much collaborator, networking and resourcing for us. I wanted to make sure that he got recognition because he's been doing some great work on behalf of us and our population we're serving.

>> If you don't mind, Tony, I think we'll leave it at your e-mail and if anybody has any questions they can feel free to e-mail you or myself or maybe we can include Kevin's e-mail as well when we send out the notice.

>> Happy to.

>> Thank you. Thank you all so much for joining us. And we really appreciate your time. Thank you, Tony.

>> Y'all have a good one. Stay safe.

>> Thank you. Bye-bye.

[End of presentation].

** Edited **

Recommendations and Findings:

- Communicating effectively with people with disabilities in emergency situations is important.
- Special considerations are also necessary for shelters, evacuation plans, and transportation.
- Recommendations include continuing allocating resources to special considerations for people with disabilities in emergency situations.