

PACIFIC ADA CENTER
WEBINAR: FEMA PROMISING PRACTICE: DISABILITY INCLUSION IN PLANNING AND
HAWAII PERSONAL PREPAREDNESS

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>> Lewis Kraus: Welcome to the Emergency Management and Preparedness Inclusion of Persons with Disabilities webinar series. I'm Lewis Kraus from the Pacific ADA Center, your moderator for this series.

This series of webinars is brought to you by the Pacific ADA Center and the collaborative effort between the ADA National Network and FEMA's Office of Disability Integration and Coordination. The ADA National Network is made up of 10 regional centers that are federally funded to provide training, technical assistance, and other information as needed on the Americans with Disabilities Act. You can reach your regional ADA Center by dialing 1-800-949-4232. FEMA's ODIC covers the same 10 regions with regional disability integration specialists. More information about FEMA can be found at www.fema.gov and then type odic into the FEMA website search.

This is the third year of this webinar series which shares issues and promising practices in emergency management inclusive of people with disabilities and others with access and functional needs. The webinars provide an opportunity for emergency managers, people with disabilities and others with access and functional needs, first responders, planners, community organizations, and other community partners to exchange knowledge and information on promising practices in inclusive emergency preparedness and management for the whole community. The series topics will cover emergency preparedness and disaster response, recovery and mitigation as well as accessibility and reasonable accommodation issues under the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, the ADA, and other relevant laws.

The series alternates monthly between ADA National Network Learning Sessions and FEMA Promising Practices. We encourage you review the series website and familiarize yourself with the full array of sessions available in this year's series at www.adapresentations.org/schedule.php. These monthly webinars occur on the second Thursday of the month at 2:30 eastern, 1:30 central, 12:30 mountain, and 11:30 a.m. Pacific time. By being here you are on the list to receive notices for future webinars in this series. The notices go out two to three weeks before the next webinar and open that webinar to registration.

For those of you who are new to this webinar series and its software, we will now review some of the features in the webinar platform before we begin the session today.

In this session only the speakers will have audio. The audio is being broadcast through your computer. Make sure your speakers are turned on or your headphones are plugged in. You can adjust the sound by sliding the sound bash left or right in the Audio & Video panel. If you are having sound quality problems, go through the audio setup wizard which is accessed by selecting the microphone icon with the red gear symbol in the Audio & Video panel.

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Also note that this webinar is being recorded and can be accessed at the www.adapresentations.org website under the archive tab next week.

You can follow along with the webinar platform, with the slides. If you are not using the webinar platform, you can download a copy of today's PowerPoint presentation at the www.adapresentations.org/schedule.php web page. This session is recorded, as I've just said, and it will be available next week.

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The Whiteboard, where the presentation slides are shown, can be resized smaller or larger by choosing from the dropdown menu located above and to the left of the Whiteboard. The default is Fit Page.

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At the conclusion of today's presentation there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform and the speakers and I will address them at the end of the session. So feel free to submit them as they come to your mind during a presentation. You type the questions into the chat box or press control m and enter into the chat area. And if you're listening by phone and not logged into the webinar, you can ask your questions by e-mailing them to adatech@adapacific.org.

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Today's FEMA Promising Practices is entitled, Disability Inclusion in Planning and Hawaii Personal Preparedness; a full and meaningful inclusion of individuals with disabilities and others with access and functional needs in emergency management process means shared understanding, cultural competence, effective communication, inclusive practices, and comprehensive emergency management principles. Personal preparedness education combined with accessible and inclusive emergency management can enable individuals with disabilities and others with access and functional needs to participant in a meaningful way with emergency managers and planners.

The first part of today's presentation will focus on increasing understanding of how individuals with intellectual and developmental disabilities, their families, and staff can better understand needs during a crisis and how they can gain skills in mitigating the impact of an event.

In the second part of today's presentation, we will have an outline of essential components to including community stakeholders in planning, structuring, planning strategies to be inclusive, and applying whole community principles to all phases of the emergency preparedness process. Activities with persons with disabilities and preparedness, planning, statewide exercises, event evacuation and responses from Hawaii will be shared.

Our first speaker today is Linda Certo. Linda is a licensed clinical social worker who has specialized in providing clinical services to access and functional needs populations at Access: Supports for Living for the past 20 years. She has been an adjunct professor at SUNI New Paltz and Mount St. Mary's College and was the coordinator at the Institute for Disaster Mental Health in 2013.

She has been a Disaster Mental Health responder with the American Red Cross for the past 15 years. Ms. Certo is a contributor for the "Disaster Mental Health Handbook" for the American Red Cross.

Linda, I'm going to turn it over to you.

>> Linda Certo: Thank you, Lewis. And thank you, everyone, for giving me this opportunity to talk about some of the things that I've been fortunate to learn in my practice.

For today I have a list of objective that I'm hoping that we're going to cover in the next 30 minutes. One of the first things I want to communicate is I'm going to be talking about individuals with a wide and varied array of abilities and skills. So it may be a little complex. I might be talking about individuals who might have issues that profoundly impact their ability to interact with the world versus individuals who have mild cognitive delays and are very high functioning. I'm also going to try to address the individuals themselves, their family and caregivers, as well as hopefully including first responders and other people who respond to events. So it's a little bit of a broad array but I'm going to do my best.

One of the first things I want to try to address in this talk is to increase people's awareness and understanding of some of the things that may occur in preparing, during, and after an event. We're hoping that the talk will begin to look at how to mitigate the impact that a crisis might have on an individual. And I'm hoping to give some clear and concrete steps that people can take in planning and also in responding.

One of the things I do want to talk about is sheltering at home versus going to a shelter. When people have options between the two, and to outline how we do some of that work at the agency that I work for, Access: Supports for Living. And I also, finally, want to talk about the importance of supporting the caregiver.

Some of the things that we want to consider about working with individuals who might have cognitive or developmental delays is that individuals who have a diagnosis like this might have difficulty processing information on a baseline, adding the chaos of emergency or a crisis can really impact on how somebody usually gets through their regular day. So that's something that we want to keep in mind.

An individual's memory and judgment can be impaired. And a person's ability to make choices in a proactive way might be further hampered by a chaotic environment or an unexpected change or difficulty in transitioning due to a crisis.

One of the things that I see often at work is that people might have difficulties communicating both respectively and expressively or either/or. Someone may be able to express themselves well but may have difficulty understanding something when it's explained to them or in the inverse, may understand everything completely but really struggle to be able to communicate their own wants and needs to those who are trying to assess.

Duress, distress, emotional reactions could result in maladaptive response. Or a person might actually have difficulty maintaining their baseline of having to interact with the world and may have additional struggles.

Sometimes people might have difficulty interacting socially because sometimes it can be very complex and nuanced. And if someone has cognitive difficulties; for example, a person who is on the autism spectrum might have difficulty navigating people's emotions on a good day but when surrounded by people who might be having a strong emotional reaction to an event around them, it might make it even more difficult for that individual.

One of the things that I found in my practice is that people tend to assume certain things about certain segments of the population. And unfortunately they also seem to do that for people with, you know, cognitive delays or cognitive needs. Sometimes I find that people just assume that someone won't be able to understand something at all and so they don't bother to try to explain it to them and will simplify things or explain something in a parentified way or not have somebody participate in the actual planning or discussion of whatever might be happening in that person's life.

Sometimes we find that caregivers in a very loving way, want to protect someone that they feel might be vulnerable for the unpleasant aspects of life so they may not share some of the more difficult things in hoping to avoid distressing the person or overwhelming them.

Sometimes people feel that individuals with cognitive needs might be completely reliant on others and can't do anything that other people can do, which is a tragedy and really limiting for anyone to have that idea about them.

Sometimes we get what we call diagnostic overshadowing where all someone sees is the most obvious diagnoses and doesn't acknowledge or even see other struggles that that person might be having; such as physical health needs or financial needs or anything like that. And sometimes I feel that people just expect individuals with cognitive delays to just be happy because they don't have the stressors that other people may and that's not true at all. People with cognitive delays have a full range and spectrum of emotions and responses. They often are complex and nuanced and ambiguous. We want to make sure that we honor that.

The reality of the situation, just to go over this again, is that sometimes people may not know how to cope with a novel situation because they've not been taught, you know, like the rest of us are taught how to respond to something new and different. And some of that might be because of shelter or it might be that someone just assumes that someone won't understand.

An individual might have a strong independence skills that don't get acknowledged. In the agency I work for we have about 100 apartments across three counties where individuals with cognitive needs live independently in the community and participate in work and relationships, and a full, loving life. And often that's not acknowledged or people don't see that about them when they hear that there might possibly be a diagnosis involving cognition.

Sometimes individuals can have psychiatric and health-related needs that can complicate their ability to respond to a situation and should be acknowledged and supported and seen as a separate yet connected aspect to address when someone's trying to help someone maintain stability or to develop skills.

Many of the individuals that we work with do have caregivers to address some of their functional needs but not all. If you do find yourself working with an individual or doing some planning with an individual, it's really foreign ask how involved is the person or is their caregiver. Is it somebody who just helps them with their bill or is it somebody who might have to help them with more physical needs that they experience, you know, for activities of daily living?

It is true that some people may have communication challenges and some may not. And some might be incredibly expressive. Or some people might just need a little bit of extra time.

There can be difficulties in processing information, so please be creative in the way that you present information to individuals. Having been a disaster responder for many, many years, I find that everyone's ability to process and remember things under duress is severely impacted. So I find that having handouts or writing things down enables people to breathe just a little bit and not have to rely on one more bit of information to carry around with them while they are overwhelmed with so much.

So some of the things to address this. What are some of the things we can do to help build somebody's independence when planning or in helping to mitigate?

This slide is more for individuals who are supporters or service providers. I want to be careful about sharing information effectively. I worry sometimes about what I see on the news; that sometimes it's not clear or sometimes the images or the language that's used is designed to pull you in and to have a certain level of excitement about watching it and finding out what's going on. And I know that some of the individuals I work with can become distressed by this because they don't always notice that it may not be happening right in their immediate vicinity or it could be something that's happening actually very far away. And sometimes seeing something over and over again doesn't mean that it's continually happening but it could be old footage that they are showing to illustrate. So sharing information, especially such as the media, but also sharing information such as appropriate numbers to contact for support.

I think that we should try to work on putting together a plan with someone. And then trouble shoot the plan. Don't just put something in place and assume that months down the road or even years down the road you can dust it off and assume it's still going to work. People's skills change. They evolve. They grow. Supports -- people might end up leaving and the numbers may no longer be active. Run through this program when you can.

Identify social supports in the community. If there's something that happens like in the northeast, a snow storm that really slows everyone down for a significant amount of time, sometimes it's nice to know who your neighbors are. And it's nice for the neighbors to know that someone may knock on their door and ask them for assistance with something.

Having information easily accessible. Always keeping it in one place. I always recommend the inside cabinets in a kitchen that we post things that can easily be found. You see it all the time, so it keeps it in your memory.

Developing communication plans. That's one-on-one as well as with the community and resources. And I'm going to talk about that more in-depth.

Again, establishing response plans for the care providers, for the agencies, and for the individuals themselves.

And normalize planning by making it a routine. We see this with something that happens in our life and it's just, you know, common. I think that that takes away some of the fear and some of the unexpected.

I have to practice something I've never practiced before. It might be something good to speak about, saying, oh, have you seen your neighbors recently? Are they still there? Do they still know that you might go to them to borrow a cup of salt or to make a phone call if there's a blizzard? See if maybe you can offer the same for them.

For individuals who have stronger cognitive abilities, you might want to actually do practices or join a local drill. I know that our medical reserve corps, Red Cross, all sorts of things practice drills in the community. Why not join in and participate?

Again, identifying social support contacts, whether it be within walking distance or within the community.

Identifying community supports such as social services, walk-in health centers that are local.

One of the things that I also think is very important is to learn safe food preparation. Knowing how to make a meal when there's no power that's safe. Learning how to keep some things in the pantries that are good for an emergency when the power is out.

One of our concerns is that as we get hit with some strong weather in the northeast, sometimes the infrastructure of our communities can be knocked out for extended periods of time. So we always make sure that if we know bad weather is coming, that people have enough medications to last at least 72 hours or as long as five days.

Encourage people to ask questions.

Again, I can't stress enough that sharing correct and current information.

One of the things I really do want to recommend, this is something we do in Orange County, New York. We register with 911. So if we have an individual who might have access or functional needs, we can send information to 911 that's non-identifying that might just say that there's an individual who lives in this address who might have communication needs. Or might have difficulty ambulating or might have difficulty processing information. This way should first responders need to come to that address, they will be prepared for helping people right from the get-go.

Again, practice.

Review successes. Nothing's more powerful than letting somebody know that they've done something before that's been helpful.

Don't wait for when there's a crisis coming to begin planning. Because that's usually communicated in a way that's very anxiety producing.

Again, make sure that there's a check for medication accessibility.

You want to do check-ins. I wouldn't wait for the person to contact you. We had a situation where we had a big storm. We assumed everyone was fine. And we didn't hear from anyone so we decided to start calling and realizing that lines were down, phones were out. We ended up having to put together a different plan because our ability to communicate was down.

Sometimes we do buddy systems. So if my home is not a good place to be because the power is out, whose home can I go to? And likewise.

We do bad weather routines; such as sending out information to people so they know they're prepared.

One of the things that I really want to stress is making sure that people are able to do their jobs during a crisis. So you want to make sure that you support the caregivers so that they are able to get into work to do their jobs or to be able to understand how to run a house or anything, an apartment, without some of the things that they may rely on, like their phones.

And again, practice, practice, practice.

So now, for individuals with more complex needs:

Again, make sure that you involve the caregivers in planning, and not just during a crisis. You want to have a list of individuals who can help and maybe flex their time if they know bad weather is coming.

I know our agency does that. We encourage people to come in if they believe there might be road closures. We want to make sure we're not putting anyone at risk in coming to work.

And we also provide cots and blowup beds and what not if someone is able to stay or needs to stay.

We train our staff for continuity of care. Everyone knows how to make sure our generators are running.

We know how to respond to needs that come up and give everyone a list of phone numbers to call.

And also, make sure that the caregiver knows that there is alternate supports in the immediate vicinity. We have an awareness of other staff who might live near individuals who might be a secondary backup.

We want to make sure that the caregivers can maintain routine as much as possible and to be very mindful of co-existing health needs.

I oversee one of the directors that oversees about 30 group homes. We make sure that we involve our individuals in our IRAs in the planning so everyone knows what to do and what could happen. We send out emergency protocols.

One of the jobs I have is to monitor the weather and send out a reminder list which we've attached -- I sent to Lewis and there is one available online, the actual one we sent out this past January -- that reminds people of all the little details that they might need to be mindful of so the staff can be prepared.

One of the most important things is identify medical or food preparation equipment that might need electricity. We make sure that we have a battery-operated food processors because many of our individuals also have health needs such as [Indiscernible]. So we want to make sure that they are able to continue to eat as expected, even if there may not be power to run an electrical food processor.

We need staff to do check-ins.

And we actually plan regardless to be able to shelter in place for 72 hours. We want to make sure that we are not caught short of supply or staff or anything that we need. And this has been a strong goal for my agency. We've spent years but we have generators for every single one of our group homes. And that, in the northeast, really does matter.

>> Lewis Kraus: Linda, can you hold on for one second?

There you are. Sorry. Go ahead, Linda.

>> Linda Certo: Thank you, Lewis.

You want to make sure that your staff can be flexible about coverage. Again, buddy sights, very important.

I've attached a pre-event checklist. This is very simplified but it's the type of thing that we do as an agency. And like I said, I do have a more detailed one that's actually that access. So this is, again, one of the things that I would strongly recommend because we found it to be so effective.

Again, I really want to be -- I know I'm going over this again, but I really want to be careful to stress that sometimes people aren't prepared to deal with an abrupt change in their environment or anything because of a storm or weather conditions. And they tend to not have an idea of how to plan. So that's one of the things we focus on. We do want to make sure that we can gently and without creating [Indiscernible], help people build skills so they feel empowered, like pioneers, or that this is an adventure that we're going to be having as opposed to presenting something that might feel frightening.

So, how can you support someone who might have cognitive or developmental delays? Be very clear as to what the expectations are and simplify them without a lot of emotionality in the message.

You want to help an individual process what the media is stating. And you also want to be really sure that you help someone remember when it's had successes before in dealing with the unexpected. Because that's really empowering.

You want to be mindful of your language and that if you're feeling stressed, that you don't communicate that stress to someone else because they may be looking to you to help them navigate what's happening that is so unexpected.

You want to honor somebody's routines. You want to respect how important things that are familiar could be to someone and try to incorporate those things as much as possible.

You want to, again, do the best you can to repeat practice and drill and make the situation as normal as possible.

Sheltering at home. Again, I don't want to go over too many things redundantly but an unfamiliar transition or an unfamiliar environment can add stress. If your government or your county is really requesting evacuations, absolutely follow that because safety first.

But if the option is that you can remain in your home and it is recommended to stay off the street, you want to be able to shelter in place for at least 72 hours.

If the situation is such that it's recommended to evacuate, you absolutely have to follow that. But you want to make sure that you make this as stable and easy and as smooth a transition as possible.

You want to prioritize mood stability during change. Again, keep things as familiar as possible.

You want to have the caregiver make all efforts to help the person narrate what's going on in a way that feels familiar or in a way that feels positive.

And you want to share information, again, simply without undue emotion.

Maintaining familiar objects, familiar people, and contact with supports as much as possible.

I can tell you, having worked numerous shelters over the years, one of the biggest stressors is rumors and fear. So trying to minimize that and to avoid getting caught up in speculation about the nature of the disaster would be helpful.

And, again, reframing in using words like exciting instead of scary.

There's some processes in place in New York State -- and I won't go into this because I know it's a national webinar -- but there's ways of registering institutions where they house 10 or more individuals under the same roof where they can get wrist bands so that way they can be tracked, so there's no chance of separation. That's an option.

And I know that there's been some individuals I'm aware of that families and providers have purchased GPS chips for shoes or the watch bands so that that is something to be, you know, an additional support.

One of the things that we should talk about is making sure that the caregivers notify the service providers regarding evacuations so that the person's treatment team knows where to find the person and they can maintain a continuity of care.

You want to make sure medical information and inventories are shared so that if there's any health concerns or medical concerns or medication issues that individuals at a shelter can provide support immediately.

Caregivers should be advocates and champion those in their care.

Indicate if they need to be able to take a break when discussing what their needs are or assistance in finding phone numbers so that they can find their providers.

You want to encourage people to ask questions and to advocate for themselves.

One of the things I will recommend is seeking a low stimuli environment for individuals who might have disability processing or might have sensory needs.

And you might want to address special dietary needs because food can sometimes be a significant support and also can be an issue at times.

Maybe providing an area where somebody can plug in a tablet or a digital device that they use.

For shelter operators, one of the things that we do in Orange County is that we have our Department of Social Services actually set up a table in our shelters so that people don't have to try to get from the shelter to another site to be able to get the help that they need. The shelter operator might want to have the contact number for all the major providers in their area. And if their area is impacting a lot of the people receiving services, invite them there so that the individuals don't have to then try to find transportation or their caregivers have to then transition them again just to be able to resume resources.

You want to make sure that the caregivers are identified and that you're able to provide them assistance in helping them keep with their individuals that they won't be separated.

Again, can't stress enough the need for quiet and [Indiscernible] spaces, respecting the routine that the individual might have.

Again, please be mindful of the individual's health needs.

One of the things I want to mention, I was working at the Boston marathon bombings. I had the opportunity to work with a family where there was a young child who was on the spectrum and his autism profoundly impacted his ability to communicate and interact with the world. He was incredibly distressed and struggling very much. We had difficulty trying to figure out whether or not this was because his mother was injured and he had less access to her or whether or not the disruption in his routine was not tolerable for him or whether or not he might have been injured because a lot of the people that I had worked with had their ear drums blown out because of the explosions. So he might have been experiencing pain similar to that. So that was one of the first things we did. We asked him to get screened medically in case there was something that he couldn't communicate.

Additional suggestions. Again, health needs that might impact their ability to navigate in a new environment.

You want to ask somebody to help. Find out what their coping skills are. The more involved somebody is and the more proactive somebody is, the less likely that they might find an event traumatizing. When someone has a sense of control over what goes on, it makes it so much easier.

When I was responding to Hurricane Sandy, I met a young man in Rockland County who had Down Syndrome. His job was like the greeter to our point of distribution. He was an active and involved member of the community who had a role in the disaster response. And he was dynamic. And that's the way it should be. Everyone should be able to participate in gaining a sense of control in community back. It was a wonderful example of how it should work.

And, again, I can't stress enough, giving out handouts to people so that they don't have to rely on their own memory is really, really important.

And when possible, please praise someone's efforts and bravery and share a thank you to a caregiver. It really does matter.

Finally, again, please support the caregiver because they have the overwhelming task in maintaining routines and providing support during a time of crisis.

If you're going to be speaking with individuals about how they are doing, make sure that you ask the caregivers and see if there's anything that you can do to help them as they help their person.

I really want to thank you so very much for your time and your indulgence in listening to some of our ideas.

Lewis, I'm turning it back over you. Thank you.

>> Lewis Kraus: Great. Thank you so much, Linda. I really appreciate it. It was a really interesting presentation.

For those of you listening, this would be a good time, if you have questions on anything that Linda presented or you want to ask her a question, go ahead and put that into the chat window and we will address that at the end of the next speaker.

Let me introduce you now to the next speakers. Dawn Skaggs is the National Director for Whole Community Preparedness and Training for BCFS HHS Emergency Management Division and is the Project Manager for the National Whole Community Planning and Training Program. Before joining BCFS, Ms. Skaggs was faculty at the University of Hawaii Center on Disability Studies and was the principal investigator for the Hawaii State Emergency Preparedness System of Support where she facilitated a statewide multiagency and stakeholder collaboration that provided emergency preparedness leadership opportunities to individuals with disabilities.

Debbie Jackson is the Planner/ADA Coordinator for the Disability and Communication Access Board, DCAB, and is responsible for the "Interagency Action Plan for the Emergency Preparedness of Persons and Disabilities and Special Health Needs" that was first drafted in 2006 and is currently being updated. The plan is the work of an Interagency Working Group coordinated by DCAB. Ms. Jackson collaborated with Ms. Skaggs on an emergency preparedness advisory group for the University of Hawaii's Center on Disability Studies and has completed the Community Emergency Response Team, CERT, training with the City and County of Honolulu's Department of Emergency Management and has actively recruited individuals with disabilities to take the CERT training in their neighborhoods.

And Bathey Fong is currently the President of the Hawaii Self-Advocacy Advisory Council, SAAC. She is a Feeling Safe/Being Safe Trainer and has worked at the Center for Disability Studies at the University of Hawaii Manoa. She has her own business as a Community Trainer for Emergency Preparedness.

Dawn, Debbie, and Bathey, I'm going to turn it over to you now.

>> Dawn Skaggs: Thank you, Lewis. This is Dawn. We're going to talk about what can happen when we look at personal emergency preparedness as a stepping stone rather than a destination. The destination then becomes full inclusion of the whole community in the planning process through universal accessibility. We're going to briefly look at some of the steps and the tools we need to create a pathway to the destination. So including the identification of social and cultural capital in the community is vitally important. After that, Debbie's going to outline for us an example of how this is being applied in Hawaii. And Bathey will share some of the far-reaching outcomes that are possible when we apply these ideas.

So one of the first steps in the transition that we need to take from dependence on government agencies to a whole community inclusive approach is a transition to an asset-based approach to planning and preparedness. So a careful look at communities from an asset-based perspective can reveal a great deal of capital.

There is, however, a tendency for us to look for political and financial capital to build leadership and leverage assets in our communities. This approach misses some of our strongest capital sources in the community; that being cultural and social capital.

So when the whole community inclusive of individuals with a disability and others with access and functional needs all engage in ownership for their own preparedness, like you see in the second image there, and they become prepared community members, they also become more than a prepared individual. They can become a community resource and a community asset.

We're going to look a little bit in more detail about that. How do we facilitate personal preparedness for persons with disabilities and access and then allow them to become a collaborative activity?

We look at cultural capital. Cultural capital can be seen by innovation in the community. Understanding the uniqueness of individuals and communities, recognizing their needs and resources, and facilitating innovative planning and preparedness efforts.

We need to find or develop personal preparedness tools that allow individuals of framework that can be personalized based on their needs and resources on their priorities and their values and yet allows innovation and ownership by the individual.

Individuals with disabilities are subject matter experts on their own needs and we need to keep that in mind as we go through the planning process.

As individuals, apply the problem solving strategies that they use on a daily basis to preparedness activities and bring new and useful ideas to fruition, they can actively increase the cultural capital of anywhere natural community.

So what is our role? The role of the agencies and the organizations to identify and facilitate this innovation and build on the natural community capacity. Building from the question of, How are people addressing personal or micro emergencies on a daily basis?

One example of capacity building preparedness tool, the Feeling Safe/Being Safe personal preparedness training that was developed as result of members of the Development Disabilities Council in California. Individuals with disabilities across the country have subsequently used this tool as a jumping off point to become personally prepared. After they are personally prepared, they become empowered to become a community asset and increase the cultural capacity of their natural communities.

So after cultural capital, we are going to look at social capital which can be evidenced by relationships. That's the next step in our path.

So the whole community inclusive planning efforts can strategically build on existing social capital. Relationships and partnerships, both natural and professional, formal and informal, are a construct of culture. These relationships are built on particular strengths and needs of the individuals.

If we intentionally build from and on to existing relationships within the community, then the community capacity can be built and what we will see as new leaders naturally and organically emerging.

Just as a tendency to identify financial capital before cultural capital, at this step there's also the tendency to identify political capital instead of social capital.

What do I mean by that? I mean, emergency managers frequently look to establish community leaders to support preparedness efforts within the community. While that is very important, those individuals who are leaders in other community activities may or may not be the leaders in emergency preparedness or that people who will be most impacting for participants in collaborative preparedness planning.

Individuals with disabilities and others with access and functional needs frequently have significant social capital. And when they become personally prepared and then preparedness leaders -- leaders in preparedness and participants in planning, they can be developed organically to promote preparedness within their own existing relationships, thereby building on that social capital and building on those relationships.

By looking at the strong social capital of individuals with disabilities, we see the strong and wide-reaching web of relationships that can be leveraged.

Encouraging and facilitating personal preparedness by the emergency manager and other agency partners can allow for these potential partners and preparedness leaders to emerge and to self-identify as resources to the community -- to the emergency manager.

If the role of agencies and community organizations to ensure that not only facilities but programs, opportunities, and communication are as universally accessible as possible; this way, those individuals who may emerge as leaders have the opportunity to do so.

Examples of that I've seen in the community are the 16-year-old boy who became personally prepared and then coached his family and special education class to themselves become prepared. Or the woman who was blind who after becoming prepared began teaching firefighters and other first responders and presenting at conferences on preparedness for service animals. Or the young lady with a disability who became the point of contact for information for her entire family and friends after a tsunami warning. These individuals became natural leaders in their natural communities in times of need and became partners with their emergency managers in the planning and response process.

So, for most community members, including individuals with a disability and others with access and functional needs, personal preparedness follows a process. So that process may look like this. Members becoming familiar with natural human costs and technological threats; members inventing their anticipated needs in disaster and their personal resources needs to meet those needs; members establishing individualized household plans including communication with family and friends and neighbors and local supports in an attempt to meet those needs. And then establishing supply kits and plans, keeping in mind they are specific and unique needs.

When individuals, families, and groups are personally prepared, they have developed a basic understanding of the threats and hazards in their community and their needs as well as some local resources that they plan to access. This provides stakeholders a preliminary understanding of the planning process and enables them to provide more useful and accurate contributions to community leaders, planners, and emergency managers.

By engaging in personal preparedness -- personal planning and subsequently community planning, stakeholders develop an organic sense of ownership and mitigation strategies and their own sustainability, making them additional community resources for the emergency manager.

Inclusive planning requires the inclusion of community stakeholders in a collaborative effort. So identifying those potential community partners is critical and it begins with preparedness.

So how do we take the next steps to inclusion? The next steps to inclusive planning are to ensure that we provide the necessary tools.

What do individuals with disabilities and others with access and functional needs require to be included as planning partners?

Because they are subject matter experts on their own needs, they really need access to accurate information, training and education, support and appropriate tools.

Consistent flexible resources. When community agencies and organizations focus on a goal of programmatic and communication universal accessibility, then individual stakeholders have the tools to fully engage as a community leader and become an important part of the planning process.

So the strategy might be: how can we make contributing to the planning process available to as many stakeholders as possible regardless of how scary that may seem at first.

We're going to look at a few tools to doing that. One example of this type of resource for involvement is a web-based training and virtual volunteer reception center that provides all community members including individuals with a disability to receive training and register to be a disaster volunteer within the State of Texas. This was developed for that express purpose to provide an avenue for people to become prepared and then to become involved as an active, specific member of a preparedness and response.

Another example would be the Hawaii Interagency Action Group. It is a model example of an avenue for prepared individuals to participate in the planning process.

So now I'm going to turn it over to Debbie Jackson to tell you about the plan and how they applied universal accessibility to create a capacity-building tool and an avenue for stakeholder participation.

Debbie?

>> Debbie Jackson: Good morning. This is Debbie Jackson. I know it's afternoon for some of the people on the mainland already. I'm going to be talking this morning about the 2009 Interagency Action Plan for Emergency Preparedness for People with Disabilities and Special Health Needs. We came up with this title before FEMA developed the term people with access and functional needs.

The co-conveners of the group included three agencies: The State Department of Health, the Hawaii Emergency Management Agency, which is now called HI-EMA, which was formerly State Civil Defense. I've been with the state long enough that I probably will call them State Civil Defense during the course of this talk with you this morning. And the last agency is our agency, the Disability and Communication Access board.

It was through this partnership we identified all the players we wanted to get involved with who would assist us in developing a plan related to people with disabilities and emergency preparedness. It included partners such as all of the county, civil defense agencies, state agencies such as the Department of Human Services, the Department of Defense, federal agencies, the Federal Emergency Management Agency, service providers and community agencies, and that involves people -- serve people with disabilities as well as other state agencies who might offer benefits for people with disabilities, also groups of people with disabilities that we know work together with us such as the Developmental Disabilities Council, the Hawaii Centers for Independent Living, and other people and individuals that actually represent people with access and functional needs, people who are homeless, people who have transportation issues, our Office of Language Access who works with people who have -- who are not English language speakers, so they have limited English proficiency skills.

Just to explain a little bit about the geography and culture, cultural uniqueness of Hawaii, we included a slide to show that Hawaii is comprised of eight populated islands. We're surrounded by water. We're in the middle of the Pacific Ocean. We are a five hours' flight from California. And we are many hours away from Japan or any of the Asian nations. So we have limited transportation options. So when we do have disasters here, we cannot just jump in our car and drive to another state to safety. We have to hunker down and depend on ourselves and our local communities.

We also have a very diverse population with no one ethnic minority -- I'm sorry, majority. Everyone here is a minority. And one of the things that we have included in our plan is the concept of ohana, the Hawaiian word for family. And what we try and do is that no one in the family is left behind. So we have that integrated into our culture, that everyone is included.

I can speak to the Asian culture, since I'm Asian, and indicate that a lot of our population here, being Asian, we do have the tendency to take care of our own families and our own ohana. And ohana includes not only your immediate family but your extended family, which could include anyone from cousins, aunts, friends, people you interact with on a daily basis.

So some of the goals and objectives of our plan included sheltering which means evacuation shelters as well as sheltering in place, emergency preparedness and readiness of people with disabilities and others with access and functional needs. So that's where Feeling Safe/Being Safe is very important to our community because we have peer trainers here that go out and train other people with disabilities how to prepare their kits and make their emergency evacuation plans. And Bathey was part of that group that initially started that trend.

We also worked with healthcare provider education where we worked with the public health nurses to train them about people with disabilities and access and functional needs.

And we also include what Linda was talking about in the beginning, to have accessible and redundant communications systems in our notifications so that when an emergency alert goes out, it happens on the radio, it happens on TV, it happens on text messaging.

And the final issue that we worked on was accessible transportation to and from the shelters. Because if people want to get to and from shelters, we are a natural [Indiscernible] area. And a lot of our areas are also very rural, like on the big island. So there is not a public transportation system necessarily to get people to the shelter.

So what I also wanted to emphasize next are some of the accomplishments, the outcomes and accomplishments, from our plan. We really included people with disabilities and others with access and functional needs in the plan. We want to hear input from everyone. Some of that involves one of the examples in our plan -- if you take a look at it -- and I didn't put the link to the url to our plan. If you scroll up to the beginning of your room in the chat box, that's where I put the link.

One of the things that we had in Appendix A of the action plan was to identify where all the beds were. Because one of the questions I get from the emergency responders is, How do we know in the community where people with disabilities are?

Answering a question like that is how do you know where anybody is in the community. People live where they live. And sometimes you can identify clusters of people but not necessarily clusters of individuals with disabilities because they live independently, live in care homes, live in different community situations. So you can't just say, oh, well, they all live in one area.

What we did was we had listed in our plan where all the beds were. And in the meantime, in the subsequent years, we have also gotten information online to EM Ops so people can go online and look at where the clusters of beds are so that they can get some idea of where some people with disabilities are located.

We had a list of shelters, emergency evacuation shelters, identified and assessed in the community. And we're probably one of the few states that actually put them on a website. However, we don't open all of them. So we are currently working on not having them listed on a website because people may get confused and think all the shelters are open when only some of the shelters might be.

For example, in our last emergency, we only had 10 shelters on Oahu open. If you looked at the list, you might inadvertently go to the wrong shelter. So we're trying not to list the shelter on a website now and encouraging people to listen to the news or watch their text messages, etc.

We also trained people with disabilities and access and functional needs to develop an emergency evacuation plan and to prepare and put their kits together.

Some of the other things that I'd like to do with updating the plan is to also include prevention and mitigation to work with response. As Lewis mentioned in my biography, what I'm trying to do is also encourage people -- not people. I'm trying to encourage the county to realize that people with disabilities are also a resource that we can tap into and we should include in training such as the Community Emergency Response Teams. And I have been successful in recruiting several deaf people to go, people in wheelchairs to go. And hopefully soon somebody with a developmental or intellectual disability will also go through the emergency response team.

In the picture I have on this slide, I just wanted to mention, we're probably one of the only states with an active volcano which has been erupting for over 30 years. So that top picture is a picture of the eruption that occurred last year. And the bottom picture is from our local emergency -- actually, we did a strategic national stockpile exercise last week that Bathey was also involved with. But these are some of the people that were involved in our exercise.

I encourage both the state as well as the county, if they are doing exercises to include people with disabilities to go and participate as actors instead of just using actors pretending to have disabilities. And I think that's one of the successful parts of what we're doing in Hawaii, is that we do respond and we do use people with disabilities in our actual exercises.

And one of the things about our Interagency Action Plan is that we actually have -- we actually set it up so that the goals and objectives are the responsibilities assigned to particular state and county agencies. And what we do is we have people sign off that they will be responsible for a particular goal or objective. In that way they take ownership of it. And a lot of the things have been coming to fruition now.

For example, in looking at our shelters, one of the things that our agency has been encouraging for many years is that we should go and look at each site and examine it to make sure that they are accessible for people with disabilities. Some of the other agencies' input is to make sure that the site is also hardened so that it will withstand the winds of a hurricane.

So we're working currently with the Hawaii EMA agency to develop shelters and a shelter plan so that we can include those possibilities. And we can include shelters that are actually going to withstand hurricane-force winds and protect people in the community when they decide to go to the shelters.

So on this last slide what I did was I listed some tips for success that hopefully if you decide to establish something like an Interagency Working Group, you can learn to identify who in the group

should be your stakeholders. And you should always include individuals with disabilities and others with access and functional needs.

You should make sure that the meeting site you set for people are accessible. And not only accessible physically but that you provide accommodations such as sign language interpreters, any handouts in alternate format, large-print Braille, electronic format so that everyone can access the information that you're going to discuss and provide to them.

And what I talked about also was that you agree to an assigned goals and objectives to key agency that can make decisions and do things within the community to actually implement your plan.

And lately, especially with this last strategic national stockpile exercise that we did, I spent a lot of time with the planning group working with them on using plain language or everyday language that people can understand, especially in the handouts. You don't want to give a handout about medication. And then the person you give it to doesn't understand what it says.

And collaborate by using existing resources. In the national stockpile plan, what we did was our agency paid for the sign language interpreters. And we made sure that what we could get in alternate format we did and to provide to the public.

And we always acknowledge the participants' contributions in whatever we're doing.

So if you would like to see our plan or if you would like more information, please feel free to contact me. There's my contact information.

Now I'm going to turn over the presentation to Bathey.

>> Bathey Fong: Hi. My name is Bathey Fong. I am the Hawaii Self-Advocacy Advisory Council, also the president for the Self-Advocacy Advisory Council.

What my life was like. I didn't feel supported. I was put down. I was a client. I couldn't speak up for myself. I didn't know that I could do a lot of things. I didn't know I could help other people.

What I did. I took an emergency preparedness class. I took a training on how to be prepared trainer in an emergency preparedness. I trained others how to be prepared. I traveled to other islands to train people.

What I've done and what I do now. I taught responders and emergency managers about Feeling Safe/Being Safe and people with disabilities. I helped other people become trainers. I hosted a table at preparedness fairs.

I speak at conferences. I participate in statewide exercises. I work with Debbie, our ADA Coordinator.

I was shy -- oh, how I changed my life. I was shy but worked on my confidence. I learned how to speak up for myself. I asked people to listen to me. I learned how to share my feelings. I learned how to not be scared and ask for help.

That picture, I learned how to surf. Yeah. I started to get more involved in other communities. So that picture I wanted Debbie to share to everybody that I've been surfing.

For people with disabilities you need to: have respect for yourself; be more confident; use your voice and speak up for yourself; make your own choices and decisions; build relationships and choose the people in your circle of support; learn from your mistakes and be ok.

Who I am today. I am the President of the Hawaii Self-Advocacy Advisory Council. I am a business owner training people about emergency preparedness. I help people with disabilities have a voice and make their own decisions.

I dream of living on my own and having my own family. I want to travel and learn new things. I want to continue helping people reach their goals and dreams.

>> Debbie Jackson: And we're going to turn it back to Dawn to summarize everything.

>> Dawn Skaggs: We hope we've provided you with a very brief introduction to the concept that beginning with an asset-based community assessment, focusing on cultural and social capital, and applying universal accessibility strategies can actually facilitate individual emergency preparedness and more. And this can be the first step in paving a way for individuals who are interested to become participating partners as we saw in the Interagency Action Plan and for them to become true community assets as is phenomenally exemplified by Bathey.

So that is the end of the time that we've prepared. I think that I'm going to turn it back to you, Lewis.

>> Lewis Kraus: Great. Thank you so much, Dawn, Debbie, Bathey. And their contact information is there on the screen. That was a great presentation.

Before -- first of all, I want to remind everybody you can submit your questions in the chat window. We'll get to those in just a second.

I did want to go back to Linda for a moment. Linda, you did post or make available your storm advisory document. I didn't know if you wanted to explain that or tell people about that. That is on the ADA presentation -- www.adapresentations.org/schedule.php website. It will be in the archive as of tomorrow but right now it's up there with all of the other slides. All the slides that you just heard are there. And as of next week all of that, this whole webinar, will be available as an archive.

Linda, did you want to say something about that document for people?

>> Linda Certo: Just that that's the document that we send out.

Usually I follow the weather. And we realize that we might have significant weather issues. I pull that document up and I tweak it depending on what weather we're going to be having. And it's just things like reminding people to know where their car charger is, to have non-perishable food items, make sure that there's sufficient medication. It's a full checklist including phone numbers and all of that. We send that out before the storm it gets posted.

The staff who are assigned to work will review it and go through the checklist. And then I end up -- my partner, Amanda Lasher, will call the people in the morning and evening depending how bad the weather is, and we ask to make sure: Do people have staffing, power, phones, and I think electricity? And then we report that back to our maintenance department or whoever else.

And that's how we basically ride through the storms here, especially when we're incapacitated for a couple of days. And it matters. The staff thanks us for thinking of them and not sort of leaving them out there to -- you know, by themselves. It really helps with communication. It does make a difference.

Thanks, Lewis, for letting me have an opportunity to explain that.

>> Lewis Kraus: Sure.

Ok. Now, let's turn to some questions. I believe this one is for you, Debbie. How did the Interagency Action Plan start or how can someone reproduce the beginning of this? Are there tips about how interagency -- maybe there are political tips about how interagency committees start or can get put together in order to get this kind of a plan put together.

>> Debbie Jackson: Well, what we did at the beginning was since this followed Hurricane Katrina in 2005 -- that's why we did it as an effort with three agencies to set it up. But we could have not chosen three state actions. We could have chosen a private, nonprofit agency that works for people with disabilities. We could have chosen several different agencies. But as long as you can work with the directors or someone within the agency that knows about emergency preparedness. Because when I first started, I knew nothing about emergency preparedness. I learned everything on the way.

So I don't think that you need to especially know about emergency preparedness. You need to know the people that do and work with them. And that's why we were fortunate to have the director of health at that time interested in the topic. Actually it was the vice director from Hawaii Emergency Management or State Civil Defense at the time that partnered with us and encouraged us. And the three of us sat down together first to come up with who the stakeholders we thought we would want to include in the group.

And since we didn't have the money to fly people in, we used teleconferencing at the time. Not telephones but we used TV as well as -- TV teleconferencing with the Department of Health and with State Civil Defense at the time to link everybody together statewide. And a lot of the conferencing came in from the Emergency Operation Centers from the counties. We did include agencies such as Red Cross because Red Cross is a very big player in emergency management here on a daily basis with the emergencies happening within the community.

But I think as long as you can get the stakeholders together and have them willing to start on the plan with you, that's where we started. And that's what helped us.

>> Dawn Skaggs: Lewis?

>> Lewis Kraus: Please go ahead.

>> Dawn Skaggs: Can I build on Debbie's answer because she is much too humble?

A major contributing factor to the initial impetus as well as the success and sustainability of the Interagency Action Plan is Debbie and her ability and focus on building that social capital, the relationships within the community. So as funding was greater or lesser, this was really not reliant on funding but more reliant on maintaining those interagency and stakeholder relationships which Debbie has really played a key part in. So she has not really emphasized that because she's the perfect example of that. That is a really important piece to the success of the Interagency Action Plan, really developing, maintaining, and prioritizing those relationships.

>> Lewis Kraus: That's great. Thank you so much. It's really helpful to sort of then connect that idea back to your talk about the social capital here. So that's great.

I also -- before I move on to the next question, I did see someone, Karen, looked like you wanted to ask a question. If you have questions, do type them in to the chat window.

Ahh. I think you just did. Ok.

And this is her question. There was once a -- the talk about a registry for people with disabilities with Civil Defense. Has that ever been resolved, identifying people with access and functional needs is still a problem? How can we reach them?

That was a question for Debbie, according to this person.

>> Debbie Jackson: Well, what we've done is I had worked with the county, the City and County of Honolulu's Department of Emergency Management, to try to get them to -- actually, this was a team effort between Dawn and myself. We worked with the Department of Emergency Management to introduce them to Smart 911. In the plan, as part of our plan, we did not recommend a registry because a registry would have required one agency to gather all the information and keep it updated. But with Smart 911, the person who wants to register has control of the information. So they can go to a website, type in their information. If they are a person with a disability, if they need medications, etc.

And we actually did start Smart 911 only on Oahu with the Hawaii Police Department last year, with the Honolulu Police Department. And they are piloting the program. The counties are looking to see whether it or not. The last time I spoke to the police department they had approximately 2,000 people registered in it. You can put information -- you can include information about your disability status. You can include information about where you live so that if 911 comes to your site they have that background information because the police department will share that information.

And I think for emergencies, the next step would be I think after the state see that this is a good way to do it because the individuals responsible for maintaining and updating the information, they are contacted every six months to update their information. I think that will be the next stepping stone to getting us into -- I'm trying to think of what it was called. Because it's not prepared 911. I don't know -- Dawn, do you remember what the program is called? It's connected with a company that will also use the information for emergency responders in the community. So we would encourage the use of that tool instead of setting up a separate registry for people with disabilities.

>> Lewis Kraus: And I'm just going to point out that this questioner is saying that she's on the big island and was wanting to know when it's coming to those islands -- that island and other outer islands.

I'm going to let the two of you have that conversation offline. There is contact information for Debbie there on the screen. You can contact her and maybe there's a way that you can work that out.

I do -- let's see. We are running out of time so I just wanted to say one thing. Linda, there's one more question for you if you can address this real quickly. Is there a way that you can explain how emergency management offices at the local level can assist or lead in the preparedness for people's cognitive needs? You talked about it in general but, like, for a local office is there a way that they can sort of be involved or is that part of what you've done?

>> Linda Certo: We have. We have worked with our local OEM agencies and the Department of Health and they basically let us know what services they can provide. They actually had a couple of people actually come in and sit on emergency planning meetings and offer some support. So a lot of the ideas that we came up with or that I shared with was part of a collaborative effort such as the 911. That was shared with me by our local radiology officer. So I guess just reach out and let them know what you could offer. See how that works from there.

>> Lewis Kraus: All right. That's fabulous.

Also, just so you all know, there is an archive that has all of our previous webinars and there was an entire webinar on registries that you can go back and listen to if you have a particular interest in registries and putting yourself on a list.

We realize that many of you may still have questions for speakers and apologize if you didn't get a chance to ask your question but we are running out of time. But you can contact -- you have their contact information here on the webinar. And also, you can contact your regional ADA Center as well at 1-800-949-4232 if you have questions and those can be answered that way.

You are going to receive an e-mail with a link to an Online Session Evaluation. Please complete that evaluation for today's program. We really value your input and want to improve and also demonstrate to our funder the value of our program.

We want to thank our speakers today for sharing their time and knowledge with us. That was really an excellent presentation.

I want to remind everybody the session was recorded. It will be available for viewing next week at www.adapresentations.org/archives.php.

Thank you for attending today's session, everyone. We look forward to seeing you at our next one on April -- sorry, on June 9, and that will be an ADA National Network Learning Session: Office of Access and Functional Needs (OAFN) Web Map - Integration Through Innovation

Have a great rest of your day, everyone. Happy day.

Good night.