

PACIFIC ADA CENTER  
EMERGENCY MANAGEMENT AND PREPAREDNESS – INCLUSION OF PEOPLE WITH  
DISABILITIES WEBINAR SERIES  
NAVIGATING LONG-TERM RECOVERY AFTER A DISASTER: THE ROLE OF DISABILITY  
PARTNERS

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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 as a 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](http://www.fema.gov) and then type odic into the FEMA website search.

This is the fourth 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. Upcoming sessions are available at [www.adapresentations.org/schedule.php](http://www.adapresentations.org/schedule.php).

The 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. And by being here you are on the list to receive notices for future webinars in the series. The notices go out two to three weeks before the next webinar and open the webinar to registration.

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

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This webinar is being recorded and can be accessed on the ADA presentations website next week in the archive section.

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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 in the chat area. 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 in the presentation.

To submit your questions, you go to the chat area box or press control m and enter text in the chat area. If you are listening by phone and not logged into the webinar, you can ask your questions by e-mailing them to [adatech@adapacific.org](mailto:adatech@adapacific.org).

If you experience any technical difficulties during the webinar, you can send a private chat message to the host by double clicking the Pacific ADA Center in the participant list and the tab titled that will appear in your chat panel, type your comment in the text box and enter. If you're using the keyboard, can you use F6 and arrow up and down to locate Pacific ADA Center. You can also e-mail at [adatech@adapacific.org](mailto:adatech@adapacific.org) or you can call us at 1-510-285-5600.

Our speakers today comprise two different parts of what our topic is. We have our FEMA speakers: Marcie Roth, the Director of the Office of Disability Integration and Coordination at FEMA, and Gay Jones, the Disability Integration Communications Specialist at the Disability Integration Communication, ODIC, FEMA. We have Yavonka Archaga, Executive Director of Resources for Independent Living in New Orleans, Louisiana, and Ann McDaniel, the Executive Director of the U.S. West Virginia Statewide Independent Living Council and Larry Paxton, the Executive Director of the Independent Living Center in Charleston, West Virginia.

So, Marcie, I am going to turn it over to you now. Go ahead.

>> Marcie Roth: Good afternoon, everybody. This is Marcie Roth. I appreciate the opportunity to talk about one of my very favorite topics today which is long-term disaster recovery. I want to thank the ADA National Network and you, Lewis, for the ongoing partnership that we have with the ADA National Network to provide information about emergency management preparedness response inclusive of the access and functional needs of the whole community.

The role of the Federal Government in disaster recovery is sometimes not as understood as we would like. So this is a good opportunity for me to provide some information to the folks who are participating today.

The Federal Government is always involved in emergency management only by invitation from the state, from the governor, and almost always only when there has been a presidentially declared disaster. For purposes of this presentation, we're going to talk about Stafford Act declarations as really the focus of our discussion.

So the Federal Government has an array of services that we can make available to states after a presidentially declared disaster and states will independently make decisions about which of the various federal programs they would like to select and that they would like for the Federal Government to assist them with.

Over the last several years as a part of the Presidential Policy No. 8 PPD, Presidential Policy Directive No. 8, also referred to as PPD No. 8, the national preparedness goal was established and the National Preparedness System was created. Within the National Preparedness System there are a number of framework documents alongside long-term disaster recovery. And among those frameworks are a specific framework that speaks to the long-term recovery initiative that Federal Government provides in collaboration with state and local government and the whole community.

So in the National Preparedness System, National Long-Term Recovery Framework there are some very specific references and explicit inclusion of the obligations to provide equal access throughout recovery.

We're going to spend some time today talking about what that has looked like in two recent current underway disaster -- federally declared disasters that are in various stages of disaster recovery.

Both states, Virginia and Louisiana, have asked to initiate the long-term disaster recovery assistance of the Federal Government. So you will hear today about some of the -- I don't know why my slides just advanced.

>> Lewis Kraus: That's me, Marcie. I'm sorry.

>> Marcie Roth: Ok. Could you, by chance, put them back a few? [Laughter]

>> Lewis Kraus: Sorry.

>> Marcie Roth: That's ok.

So the National Preparedness System speaks to National Disaster Recovery Framework, as I previously mentioned. And I will very specifically refer to one of the examples of what you will find throughout the National Disaster Recovery Framework and that is that care must be taken to assure that actions, both intentional and unintentional, do not exclude groups of people based on race, color, ethnicity, national origin -- including limited English proficiency -- religion, sex, sexual orientation, gender identity, age, or disability. Care must also be taken to identify and remove social and institutional barriers that hinder or preclude individuals with disabilities and others in the community historically subjected to unequal treatment from full and equal enjoyment of the programs, goods, services, activities, facilities, privileges, advantages, and accommodations provided.

So, in short, what that is saying is there is an obligation to provide equal access throughout the process of disaster recovery and that people with disabilities are entitled to equal access and full inclusion throughout the process and that the role that we all play collectively is to provide guidance, technical assistance, and input to ensure that that equal access is, in fact, the experience of disaster survivors with disabilities.

So I will often talk about the yin-yang symbol when I talk about disaster recovery. Disasters are certainly considered a crisis. It's inherent in what they are. They are crazy, without a doubt. But with every crisis comes an opportunity. In fact, disaster recovery is an extraordinary opportunity to use the legal obligations to provide equal physical program and effective communication access and to comply with the obligation associated with every federal dollar to provide that access, to build towards universal accessibility rather than simply meeting the compliance obligations that are inherent.

So, I'm not sure where we are on the slides at this point, so if you could go to the next slide, please.

Thank you.

One of the many strategies that FEMA has used to engage our communities as partners in long-term recovery has been the creation of agreements. We currently have memorandas in place with the National Council on Independent Living, the National Disability Rights Network, two of our longer-term MOAs. More recently we developed one with the Pass it on On Center. And about a little more than a year ago with Portlight. And our most recent MOA that has just been signed within the last couple of weeks is with the Association of University Centers on Disability.

We have relationships in place that allow us to reach out to Independent Living Centers, Protection & Advocacy Services, assistive technology re-use, the services that Portlight provides across the country in meeting the needs of disaster survivors, and most recently as well, of course, with AUCD, the Association of University Centers on Disability, to engage all of the University Centers as partners in providing technical assistance to communities that are engaged in the process of disaster recovery.

So next slide, please. Among the many issues that we are working together in the states that have active disaster recovery underway vary from the complexities of accessible housing to ensuring not only that schools are physically accessible but, in fact, that students with disabilities are going back to school along with their peers, that we are collectively working together to optimize the investment that are being made in community resources, in capacity building initiatives, and that the emergency preparedness efforts that communities may have a heightened attention to in disaster recovery, that those are baked in the actionable steps that people with disabilities equally participate in as communities to prepare for and begin to implement the efforts to be ready for whatever may come.

One last point I want to make is that because every federal dollar must comply with the Rehabilitation Act, there is a tremendous amount of money that is invested during disaster recovery. And these dollars are also invested in what's called hazard mitigation. There is a responsibility to invest 5% of the federal dollars that come into a state in hazard mitigation. Again, the Rehabilitation Act applies to the expenditures. And so these are tremendous opportunities not just for compliance but rather for universal accessibility as a part of the work that is being done across whether it's housing, employment services, the efforts that local communities are taking to be better prepared moving forward.

I think that is the end of my slides. So I'm going to turn back to Lewis to introduce the folks who have been most effectively engaged at the local and state level to hear from them in the work that they are doing.

>> Lewis Kraus: Thanks, Marcie. I'm going to turn it over now to Yavonka Archaga, Executive Director for Resources for Independent Living.

>> Yavonka Archaga: Yes. Can you hear me well?

>> Lewis Kraus: Yes. We're fine. That's great. You're going to have to turn off one of your two devices. Either hang up your phone or don't be on the speaker.

>> Yavonka Archaga: Ok. I don't have the phone on. Is this better?

>> Lewis Kraus: That's better. Thank you.

>> Yavonka Archaga: Ok. Good. I'm sorry. I had the volume up when I listened to Marcie.

Thank you all for joining. Welcome. I am the Executive Director for the Independent Living Center. I have an office in New Orleans area as well as the Baton Rouge area. As you will find, I have been experiencing disasters for quite some times over the past few years or so. So my goal is to explain to you or try to give you a picture of my relationship with FEMA and the way we have been responding and collaborating together in response to the most recent flooding that occurred in Baton Rouge.

Next slide, please.

As a part of collaborating, communicating, interacting with FEMA, we work under the relationship established with a Memorandum of Agreement through the National Council on Independent Living. And through that we have worked to collaborate with FEMA to address the needs of the consumers that we have found, especially in this most recent disaster, has yielded optimum outcome.

On the onset of disaster, we have identified that when working with consumers in the shelters and in the community that some of the things that were brought to our attention that we were very useful in doing is assisting individuals with the registration process and particularly assisting them with understanding procedural and processing issues as it relates to FEMA and the program that are available and also at the state level as these things are developed and prevented. And also, my staff worked with consumers and FEMA to address different datelines as they were occurring and being announced.

Overall, we found that the consumers had more concerns with what to do and what to do next, having problems with denials and appeals. So our organization, our Independent Living Center, worked with FEMA in teams. FEMA had about six or seven teams that they had designated. And we worked with the Disability Integration Department that Marcie is the Director of. We found that what we would do is work with those individuals' teams to identify where the needs were or what the requests were. And because we have that specialized skill set level, we were able to assist individuals to regain their independence and sustain it in more livable situations as it relates to what's available at the time.

Next slide, please.

So, the way we did this was, as I mentioned, conducting meetings and working on coordinating those services. There is two ways of this. The immediate needs that we had to address with things that people would normally think of in terms of [Inaudible]. But the things that they don't consider is what goes into assisting individuals to get those.

So the core services we were charged with as a Title VII center is very valuable at this point because we have to do a lot of things that others who may work on disaster case management are not aware of what those needs are or how to navigate the infrastructure or

lack thereof to assist consumers to obtain these services and goods. So the FEMA's Disability Integration Division was very, very useful in assisting them -- down us to be very, very useful in assisting them and the consumers.

In terms of a long-term service that we provide, the one thing that I found dealing with disasters over the past 10 years is transitional plans. It's very crucial. I'm glad that we were able to give this concept to FEMA in the process and explain it to them how we work to assist individuals to do these transitional plans because it's more of a long-term type of service that we're providing to assist consumers, to obtain healthcare organizations in these newly defined areas, this new community that they're transitioning to.

By communicating to FEMA's Disability Integration Division and other individuals, other organizations, we get a lot of referral from FEMA and the VAL. And now they are of the mindset of what those referrals look like that come through our Independent Living Center. So from that, we meet at the host, an office that FEMA has right now, an office located in the Baton Rouge area. And what we do is whatever requests have come through, we'll assist them with FEMA appeals, finding alternative resources for goods and services, and then referrals to any state Catholic charities, the voucher case management organization that is doing it for this particular disaster.

Importantly, we have done this in the past but we found that through our relationship with FEMA, us working at the DRCs, recovery centers, has been instrumental in not only helping provide for consumers with assistance but also assisting them with accessibility issues, making sure that they have the right equipment there, or if there's the need for something that the consumers can make sure that they access it and still be able to function with the accommodations and accessibilities.

I don't think I have another slide.

Lewis?

>> Lewis Kraus: Ok. We got it. Thank you, Yavonka. I'm going to turn over to Gay Jones, the FEMA Communication Access Specialist.

Gay?

>> Gay Jones: Ok. Thank you for having me. I think that as a disability integration advisor, we have set up a lot of partnerships with local organizations like Yavonka talked about. And once those partnerships are set up initially, we start going into recovery, we start thinking about doing what we call long-term recovery groups. And what I want to learn is the differences between what we talk about in terms of long-term recovery groups versus the national disaster recovery coordination or the federal disaster recovery coordination. You'll hear those two different terms. One, the long-term recovery groups, are basically on the local level.

And let's go to the next slide. I flipped my slides around.

The long-term recovery groups are, in this year, used by the impacted community to address a lot of identified unmet needs. And this is a very grassroots organization, usually set up by the Voluntary Organizations Active in Disasters or what we call VOAD. We also were able to bring in disability organizations and other community partners that have resources or are able to find resources to meet those unmet needs.

Normally these groups are very, very community-specific. So a lot of times in a disaster, that -- it depends on the severity or the impact within the community whether or not they have long-term recovery groups. And there are some disasters that don't go into long-term recovery. Depending on the disaster, you will then, on the federal level and state

level, start bringing in an assessment team to make determinations whether or not you want to bring in what we call higher level teachers.

Let's go back to the previous slide now.

If there's catastrophic impact within the community, you will see people coming in and talking about six different areas of housing, infrastructure, health and human services, economics, and capacity building. Some disasters may only have one or two of those components. It may have a housing component where a lot of housing has been destroyed and there's a need to bring in state and federal resources to work together to see how they are going to mitigate that.

Economics, people talk about economics in a community has been severely impacted. I'm going to give an example of West Virginia because I work in West Virginia. There was a community that previous to the disaster was a logging community. This community was severely impacted by the recent flooding. So in that particular community they were looking at how they could rebuild that community economically by looking at other types of economic activities that could replace the logging industry.

So that's kind of an example of what FEMA might do at that level. And at federal and state level, it is really, really important that we bring disability groups into that's because once you bring the disability groups into those two processes, whether it's long-term recovery group at the very local level or the national disaster recovery at the state and federal, you really want to have your disability organizations in all of those pieces. That way you're working bottom up and top down. That is the difference between the two types of programs that may happen depending on what the needs are in a particular disaster.

And that concludes my presentation.

>> Lewis Kraus: Great. Thank you, Gay. We're going to go now to Ann McDaniel and Larry Paxton, the Executive Director of the Statewide Independent Living Council in West Virginia and Larry Paxton, Executive Director of the Appalachian Independent Living Center.

Ann and Larry.

>> Larry Paxton: Thank you, Lewis. I'm probably not the best speaker you'll ever hear but I do now know a little bit about going through a disaster.

Our center was located in a flood area, of course. And since West Virginia is kind of a mountainous region, we had some experience with flooding. We also went through Horatio but we didn't have anything compared to the flood on June 23. But fortunately we were involved in an emergency preparedness prior to this flood and it gave us a chance to work with county groups and first responders to ensure that people with disabilities were included in their emergency preparedness plans and other aspects.

We also provided training for people with disabilities, as far as making survival kits and how important, you know, they were to have ready. And this became a valuable piece of training that we have in place because a lot of folks, including me, had to use that.

All of our staff at our center, except one, was personally effected by the flooding. Until you go through it, you don't really realize how important it is to act as quickly as you can to meet unmet needs.

For the first several days, the staff were trying to clean up their own properties and get their own houses in order. We were basically cut off and isolated. There were no telephones, electricity. There were mudslides, washed out roads and all of this that isolated us. There was no place to buy anything. When you go through that and think of what people with disabilities go through during a disaster.

So once we came through that stage and they did get the roads cleared, we finally got to the center. It was luckily spared. So we were met with a lot of calls from people with disabilities. We worked with a lot of these folks prior to this disaster. They called us regardless of what their need was.

So we began working to assist these people. And one of the services we provided was peer counseling and support. Since the staff had gone through this, we were really uniquely qualified to talk to people with disabilities because there's more to it than getting things replaced. That's very important. Also, there's a mental health side of the issue. You never forget it once you go through it. I think this is something that people need to realize when they're working with people with disabilities right after a disaster.

We also did things similar to Louisiana. We helped folks apply for help through FEMA from the Disaster Recovery Centers. And as I said before, we had gone through the process. We knew a little bit about it. And, of course, we learned a lot more as time went on.

But really, my experience through this was one of the greatest needs that folks with disabilities had in our area, replacement of medical equipment such as wheelchairs, hospital beds, and other assistive devices. We had established a loan closet, as all the centers near West Virginia have. So instantly we were ready to give out things. The very first day back in the office we were giving out things to folks that were calling and just trying to get things to folks any way we could. So that was the immediate response that we dealt with.

>> Lewis Kraus: Larry, do you mind putting the phone a little closer to you? You're getting a little faint.

>> Larry Paxton: Sure. Can you hear me better now?

>> Lewis Kraus: Yeah. That's great.

>> Larry Paxton: Ok. As I said, you know, we gave out things from our loan closet. The need was so great, we decided to collect additional durable medical supplies and equipment. And all the volunteer groups and people in the other centers, they started donating equipment and things. So we had to rent a space to store this. We used that -- are you there?

>> Yeah, Larry. You're still on.

>> Larry Paxton: Ok. So we had to use that as the collection and disbursement center and it really came in handy.

The one thing I would stress in the little part of my talk is how important those needs are to be met quickly. One quick example, there was one lady had a child that had spina bifida, in a wheelchair. So this child needed another wheelchair. It was either be carried around or get another wheelchair.

Those are the needs that impacted me. We developed a passion for getting to them quick. Once you go through it, it makes all the difference. So the impact of this on long-term recovery created a lot of challenges. One which have was funding to address these emergency needs.

Lewis, can we go to the next slide, please?

So, we then became stronger involved -- by the way -- VOADS, Voluntary Organizations Active in Disasters. We did this for several reasons. We had to have help as far as knowing where additional resources were to identify for folks with disabilities. Also FEMA was giving us several referrals to try to meet unmet needs. So we had to try to learn all we could about what was available.

So we began participating in weekly calls. And this gave us a huge opportunity to identify resources. We would brainstorm about needs specific groups or people had and what

other organizations could meet that need. And it also gave the Center for independent living a unique chance to do some advocacy as far as making sure these groups included people with disabilities in all aspects of providing services as well as being in the planning process through every stage in the long-term recovery.

This didn't come without, you know, some challenges. So you know, we realized that there wasn't a lot of understanding about people with disabilities. They weren't used to bringing folks with disabilities to the table. And every chance we got, you know, we would bring that up and get them to understand how important it was. So it gave us an opportunity to advocate for inclusion of people with disabilities.

We made progress. There's been substantial progress made as far as getting these groups to respond and respond quickly. One of the biggest obstacles we have right now is, of course, funding. It's hard to meet these needs when you have to go out and go through all of these different agencies to try to find someone to do that particular thing.

So we realized we were going to have to be a part of a larger group and work with so many other groups and agencies. That's where Ann McDaniel kind of came in and saved the day for me. She served as the lead person to basically forward e-mails, set up meetings, and keep everybody in the loop. That's been invaluable because we were trying to meet the immediate needs of our center.

Having said that, I'll turn it over to Ann McDaniel and let her talk about some of our long-term recovery efforts.

>> Ann McDaniel: Thank you, Larry. Larry and I kind of have a mutual admiration society going on as a result of what we've been through with this disaster.

Just to briefly talk about immediately what happened, a lot of us were saying: What can we do? How can we help? As a Director of a SILC, Statewide Independent Living Council, we don't provide direct services to individuals. So finding people and helping people didn't feel like a role that I had the ability to fill. But what I did feel like I could do was to make connections to get people connected with where they could get help, to get disability organizations connected with FEMA and Portlight and other entities that were responding to the disaster, to get state agencies connected to those conversations so that we could find the best ways we could to meet people's needs and to make the jobs of the folks who were out there on the ground easier because it was going to save them having to dig and try to find those kinds of connections.

So we started out with a phone call on a daily basis that grew over the first week probably to include lots and lots more people so that everybody knew what was going on with the FEMA disability folks, everybody knew what was going on with the Center for Independent Living and the other folks on the ground. And those of us who weren't out there in direct response were able to find more information and make connections and keep the communication going.

Larry, at one point, I think was on five phone calls a day. He started backing off on those and letting some of the rest of us deal with that. And then we would touch base to share information or to get updates so that we could keep that loop closed for communication.

Since that point in time, since we've really moved into long-term recovery, our roles have changed again.

Lewis, if you would advance to the next slide, please.

We're still having regular phone calls to keep people connected, to keep updates happening both ways with FEMA. We were included in a meeting at the Joint Field Office, the

JFO, of FEMA, to meet with the disability integration staff to talk about gaps and service needs and other ways that this group could work together to make things happen more quickly for people. We have had meetings with the state coordinating office, which is West Virginia Homeland Security and FEMA representatives at that same JFO to make sure that they were aware of what was going on with the different disability groups that they knew who to connect with regard to the needs of folks with disabilities.

And hopefully that they could help with resources to meet the needs of folks with disabilities and to help the Center for Independent Living be able to be as responsive as possible with the limits on their resources.

We had a phone call with the federal disaster recovery coordinator from Region 3 and the FEMA staff to kind of get everybody connected at that level for long-term recovery. We have put together a group working on identifying the pressure points basically on school accessibility. We've had multiple schools that were damaged in the flooding, some of which are not going to be useable and are going to eventually be replaced. And the students from those schools are going to other schools in the county which are now horribly overcrowded. I truly don't know how they're functioning.

So we knew that there was going to be rebuilding but that there was also going to be modular school, modular classrooms, temporary, portable facilities to get those students back in their own communities and to spread that school population back out into really situations that were more manageable.

We have a great deal of concern about the accessibility of those modular units. We were able to get connected with the help of FEMA with the School Accessibility Task Force. We've been having regular calls with regard to that. And actually had a call today that included a gentleman from the school building authority that is the coordinator for what's going on at the state level with both the bidding process and selection process and implementation of the modular units but also with the school rebuilding so that we can have an influence over insuring that accessibility is included in everything that they are looking at; that students with disabilities are going to be able to go to their homeschools and be able to function. I found him to be a very open gentleman who is a sponge and ready to soak up everything we can share. We're going to have ongoing conversations including him. So those initial efforts really are going to yield some long-term benefits, I think, not just in response to this particular disaster but in school buildings, activities going forward statewide, regardless. So we're really happy about that.

We have not only sought the involvement of our West Virginia State ADA coordinator but we were able to get her connected today. I think she's going to continue to be involved and the schooled building authority folks see her as a resource, which was our hope is, that there would be a strong connection there and she could help ensure that they understood what their responsibilities are under the law.

Next slide, Lewis.

We do have some lessons learned and many more coming, I'm sure. One of the things that we believe is that the Office of Disability Integration Coordination at FEMA really should have a budget that includes resources to address immediate needs of survivors with disabilities. Those immediate needs that happen before the regular FEMA financial assistance comes to the state, when everybody is struggling and, as Larry said, those immediate needs make all the difference in terms of being able to move forward. So we'd like to see that

happen. We intend to advocate for that and have already started the process of advocating for that.

We have found, not to lay blame on anyone, that the disability integration specialists really, when they are making referrals for unmet needs, when they are making referrals to the Center for Independent Living and to Portlight and to other folks who are actually going to be making the effort to directly meet needs, that they need to include as much information as they can. One is to verify that the need is related to the current disaster because sometimes it's not. People jump on the bandwagon. They think, oh, now I can get help with this.

More specific details on equipment that's needed. Confirm that the lot situation with the house and the design of a house -- if their ramp was washed away and they need a new ramp, is the lot going to accommodate a ramp that's in compliance with the requirements of the law? Sometimes it does. Sometimes it doesn't. Different kinds of things like that.

If you haven't been there and see the site, if you haven't been there with the person and seen the need, it's harder to respond quickly. And the more communication that can happen and the more details that can be provided, the easier it's going to be to respond quickly.

The Disaster Recovery Centers have been amazing. Larry and his staff did a yeoman's job of connecting folks with those places. We'd like to see them provide information on the grants and assistance they may be eligible for before referring people to the Small Business Administration. We know that's a requirement right now. Our issue is that scares a lot of people away if people don't have the money to pay back a loan, they are overwhelmed by the thought of even applying for one. If they could be determined eligible for those other types of assistance before they're referred to a loan situation, that would be an easier process for people to go through and could, again, make things happen more quickly. So we'd like to see the FBA loan process be a last resort for folks.

Next slide.

We'd love to see FEMA funding go to Centers for Independent Living. And I bet Yavonka would agree. If there was designated funding to address the needs of survivors with disabilities that could go through the local Centers for Independent Living who are already working with those folks, who already know what their needs are, response could be a lot quicker and it would be less taxing on the limited resource that centers currently have.

The resources for the Centers for Independent Living and other Centers for Independent Living really could benefit from attending FEMA training. We did have the L197 training offered in West Virginia with our current flooding disaster. I think that that helps a lot with folks becoming more aware of the FEMA processes and procedures and to help in our responses to folks with disabilities who are survivors of the disaster.

One of the things that was recommended is that transitional shelter assistance be used and established in some way other than hotels, motels, bed and breakfasts, etc., things less costly and will better meet individual needs. That's a big order but we think that's something that needs to be looked at and talked about and to see if we can make improvement there.

Next slide.

So what is there left to do? I'm going to leave this open to everybody. I know in West Virginia the partnerships are continuing and will continue. We'll continue to do ongoing advocacy that folks with disabilities be included in disaster planning as well as disaster response. That response is made accessible to all survivors, including survivors with

disabilities, and that we continue to educate the folks with disabilities whose lives we touch about the need to be prepared, to learn more about disaster preparedness to have their disaster kids ready. Because as we all know, and if you haven't learned it yet, you will eventually find out, just as disability can happen in an instant, so can disaster. And the better prepared you are, the more likely it is that you're going to come through it in the best shape that you can.

The other thing that I would add is the ongoing communication is critical. The more communication you can establish and maintain before, during and after a disaster, the better results you're going to have all the way around, particularly with regard to the needs of survivors with disabilities.

With that, Lewis, I would open it up to other folks to add in what is left to do and whenever you're ready for questions.

>> Lewis Kraus: Ok. Others, do you want to add in before we go to questions?

>> Yavonka Archaga: This is Yavonka, if I can.

>> Lewis Kraus: Go ahead.

>> Yavonka Archaga: Ok. I just want to kind of, like, echo the things that Larry and Ann said, what's very, very important for individuals to know and understand. Until you've gone through it, you can understand it better and we can all appreciate that but let's not just think -- it's very, very good, Ann was saying about having a disaster kit. But something I want to add to that is alternative places that you may stay. Some of the challenges we came up with is once an individual is put in a shelter, then for different options of TSA, if you have family members in other states, please know that the TSA transfers with you, that you can go to hotels in areas in other states. Hopefully get some transportation to get consumers there.

Other surrounding counties -- educate individuals on going 20, 30 miles out because that's the likelihood of having availability. A lot of times just in the area the disaster happens, that entire area effected is overpopulated where there is not availability.

And then also consider -- like Baton Rouge is a big LSU town. Hotels are booked for months, years in advance. So that you need availability, very limited.

Another thing I want to say because I don't want to take up too much time is in time of referrals and case management, for FEMA to refer things out or look for other agencies to get services, those organizations, agencies, are affected as well are getting heavy demand. So it makes those resources very limited as well.

So when Ann made the statement, speaking the same language, that the disaster kit is happening, we're in it, it's live, it's CART, it's live feed. We need to have the resources and the funding to minimize long-term financial issues, to minimize getting things done in a more -- to optimize in a more effective way.

I know my center is always going to be a call because throughout the years, without a disaster present, we are the go-to people. We are the people that are in the community assisting individuals. So when a disaster hit, you know, naturally we're going to be the people to call. So it will really, really help if -- whatever the funding is, that those funds go to the Independent Living Centers to assist in the response. That's all I wanted to say.

>> Lewis Kraus: Ok. Larry, did you want to add anything?

>> Larry Paxton: Not really. I think Ann and Yavonka touched about all the bases. It's a big process and a long process. I know here we still have people living in tents. We still have people with no power. We have people that are facing wintertime in a matter of weeks and those are the folks I'm concerned about. That's why I stay involved in these calls, to make sure

that someone with resources are trying to meet these needs. So it's a process. I know that's a big challenge. It's something we've got to just not forget about. It's an ongoing thing.

>> We have roads that are gone that won't be rebuilt for two years. We have schools that are unusable that are going to be torn down and won't be rebuilt for four years. So it's a very long-term process. The better we can meet immediate needs, the easier it's going to be for everybody to survive that long-term process.

>> Yavonka Archaga: Just to add to that, we still have communities in the New Orleans area that have not come back fully. And that's from Katrina and Rita.

And just one more thing I want to add, off of something Ann mentioned in lessons learned. Self-determination is huge. That's something we advocate for. I think when FEMA representatives need to be educated on when a person identifies themselves with a disability instead of you saying I think I have a disability. So that was some of the challenges, some of the things we really had to get clear with them. Is this a person with a disability identified themselves a disability? I would say if not, we have to move on because that's what our group does, our organization does.

So in terms of that level of education as well, Ann, I just wanted to point that out, that that was one of the challenges we had. And once we pointed it out, it was an education on the ground basically. They were like, ok, that makes a lot of sense. Thank you very much. So we saw a lot out there of the Independent Living Centers not just delivering a wheelchair or delivering a walking cane or delivering other goods that individuals may think we're doing.

So yeah. That's about it.

>> Lewis Kraus: Ok. Thank you all. That was a tremendous presentation. Really, I think everyone in the audience is pretty -- will agree with me that that was really extraordinary.

For those of you in the audience, this is your time to write in your questions. You have these incredible resources of people who are working on long-term recovery right now. And if you are not and you are trying to prepare for it, this is, who you want to talk to.

I've put the contact information on the slide. Please take it down. They said they are willing to talk with you even offline at any time. So do contact them if you need. In the meantime, I am going to start on some questions while you guys -- while you're all writing more questions.

The first question for you. I think this came up during the West Virginia part of the presentation but probably Yavonka, you can also respond as well.

Can you talk more about how you approached the peer counseling aspect with disasters for people with disabilities? What are some effective key principles that other CILs can use for planning from providing peer counseling and support during recovery?

>> Larry Paxton: I think just the fact that that person you're across from knows that you've gone through it and that you understand how important their needs are. It takes away a lot of apprehension. I think once they realize that, then they become a little more at ease. It's kind of like having a new disability. You think, I'm in this all by myself. Then you meet someone else and someone else that has the same disability. And you realize, you know what, I'm not in this alone. There's other people trying to come through this same situation. And if you work through it as a process, then you'll make through.

And, of course, along with that, you know, you have to know what the resources are and you have to be able to explain to that person how they can get help, the best way gone about it. Our legal aid in West Virginia is helping people with appeals. That was one of the challenges. I don't know if it made our list or not but some of the folks that answer the phone,

FEMA, don't talk with the folks on the disability integration side and they get denied. And that's a big blow to a person with a disability. I went through it. I lost a power wheelchair. They didn't think that was a medical necessity or an immediate need they needed to deal with.

So these are the things, just letting them know that you've gone through it. You know what they're going through. Give them as many resources as possible. And also, we don't want to forget the crisis counseling end of it. It comes back. So these are important things that you need at least verbalize and share with these folks.

I hope that answers your question.

>> Yavonka Archaga: I'd like to speak about it from my personal experience as well. Just going into the shelter in Baton Rouge, I had someone who had to prepare me for that. A lot of it comes back.

I think the times that come to mind is, first of all, validation is one thing is validate their feelings because we can understand what they're going through. Listening, listening has been a huge aspect. A lot of times individuals just need you listen.

And then we find that, you know, FEMA and the Red Cross come from all parts. Individuals are excited to speak to someone who knows the area. That gives them a sense of comfort.

And from our perspective, peer counseling and peer mentoring and sharing with each other has been very beneficial just setting up doctors, new doctors in the same area, and traveling together and talking about how individuals, different programs, how you got a manufacturing housing unit, FEMA, in their process or whatever programs are out there. How did you apply for something? They didn't ask if you had a disability or not so that you can talk to them. Make sure you tell them these things.

So we've been -- we've worked on making sure that we stay in communication and keep others in communication with each other to help each other out.

I hope that answers your question as well.

>> Lewis Kraus: All right. Great answers.

Next question. In addition to funding IL centers, should we consider funds for a state-wide coalition to better coordinate before, during, and after events?

>> Yavonka Archaga: Repeat that for me, please? I'm sorry.

>> Lewis Kraus: In addition to funding IL centers, should we consider funds for a statewide coalition to better coordinate before, during, and after events?

>> Ann: I think there are a lot of mechanisms already in place for planning for disasters. What I think our efforts really ought to be focused on there is making sure that disability organizations and people with disabilities are included in the planning processes.

I always kind of struggle when there's an effort to create another new something that is going to take people's time and people's resources, whether there's resources provided to support it or not.

I think I mentioned earlier that for a while there Larry was on about five phone calls a day. He didn't have time for that. He was busy trying to address the needs that he had because of the disaster, the needs that his staff had, and the needs that his consumers and other people with disabilities in his service area has.

Sometimes adding on another layer of meetings and conversation and time consumption can be more harm than help. But I really want to emphasize, again, the need to maintain that communication. Whatever venue you have to do it, whether it's doing ongoing conference calls, whether it's getting included in an existing conversation such as VOAD or the

disaster planning groups or your state coordinating entity for disaster planning, trying to get on what already exists and make sure that the needs of folks with disabilities are a part of the planning and part of the discussion to me would be a really key piece of long-term planning and ongoing efforts to respond well if and when disasters happen.

>> Larry Paxton: I agree 100% with what Ann just said because in West Virginia, we're right now coalition poor. I read an article in the paper this morning about another little committee that was established in Clay County to deal with this. Well, now there's friction between the different groups. That's the last thing we need is a turf war about who is going to handle what.

So I don't know how it is in other states but West Virginia has a pretty good system in place. It seems like when the money comes in for a disaster recovery, it goes to the usual suspects. And a lot of it goes to planning, which is well and good but there needs to be a piece carved out for folks like the centers that actually, you know, is where the bottom line is eventually. It all trickles down to us and we have no funds to deal with it.

>> Yavonka Archaga: Ann and Larry and I, I promise you, have not talked about any of these things in great details and I promise you we're experiencing the exact same things. When it's at the state level, especially Louisiana, we've gotten a lot of attention, a lot of money. They have it set up really nicely. There's nothing carved out for the specialized skill set that Independent Living Centers provide. However, we're doing a lot of work and a lot of responding. I am going to say from the center's perspective, I think they have a lot of things in place and the funding that's coming, however, Independent Living is not at the table as a major player. We do sit on conference calls.

I want to give kudos to FEMA for making sure that we're getting the information and that we are staying at the table and providing us the information that we are not getting. For our state, we're not large. Independent Living Center, our Independent Living Centers are not these large masses of organizations. We do great work. We've been fixated on community. But we're not very large so we're not always at every table that we should be at. And we're working to change that.

A lot of times from my perspective I can speak, I've been in recovery mode. Even trying to set up for new programs and new things. So for us now to carve it out differently on how we're going to respond, it's refreshing to me because I think we need to make systematic change, systemic change. And this is one of the things that we're doing to do that. So I think we're headed in the right direction for that.

>> Lewis Kraus: I wanted to sort of follow up this last point you were making, Yavonka, in general. Earlier some of you referred to the planning that you did and I'm kind of interested for maybe a lot of people listening as well, everybody talks about planning, planning, planning and everybody's getting prepared. And now you have experienced a disaster and have done the recovery. How much do you think, you know -- what's kind of what you learned about your planning process and how well it related to what you ended up having to do and how you dealt with it?

>> Yavonka Archaga: Can I go first or, Ann or Larry, do you want to go first?

>> Ann McDaniels: Go for it, Yavonka.

>> Yavonka Archaga: Well, it takes on different shapes because there's just some things you can't plan for. There are just some things that you can tell it to me all day long and tell me all about it but until I experience it, I understand it better. So that's why in terms of where would you go that is 30 miles outside of here, it's a different plan. What would you do is a different

plan. Maintaining the last time you got your chair from Medicare and what is that timeframe for you to get it next is a different way to plan.

Before we planned based on what we thought we were planning for but now -- I really do appreciate with my staff and some of the transitional plans in working with individuals from a planning perspective and those individuals that have done it with us, it's even easier because we have different levels of questions.

So we find ourselves -- and it works really well with the consumers that we have who have been affected or may be affected that we found and how they've responded and how they've peered with other people in terms of planning. Knowing, ok, I'm going to go to New Orleans or I'm going to go this way. That helped us. Even when the question is being asked, well, we're going to send you to the shelter, no, send me to the shelter in Gonzalez because I know I'm going to go to my backup place or my family member that lives out in that area. So that has helped us a lot.

Then there were just other things that's very difficult to plan for because we rely so much on our state infrastructure that we don't know it's not going to be there. For example, Louisiana, in Baton Rouge, the City of Baton Rouge was shut down for about a week, almost a week. And other agencies are shut down. So, you know, it's only so much that can be done and it's only so much that you can take.

What we've done is we're looking at different types of mobile vehicles, mobile [Inaudible]. So those that can break down and be put in the trunk of a car. And you can still use them. So that's fairly new for us and we're really excited about that. So we're really trying to see who we can give that to.

But it's a different way that we're planning even different stages, different areas. We're making the plans better as we go. Because what we thought we were doing after Katrina or Rita, we found what was different so we're constantly changing and getting stronger and better and educating the children as they educate us. Let me repeat that, as they educate us on what worked and what didn't work.

>> Larry Paxton: I'd like to add a little bit to what she said there. We planned. We were involved in a project called tap to talk. First responders use that for people with communication needs. This is something that can be applied to folks with communication needs. But you really don't know what's going to happen or what type of disaster. It's kind of like right in your wheel. It's the kind of thing you don't want to deal with but you do. And you can't cover all the bases. You try to cover in your mind what you would imagine you'll go through during the disaster.

We were a little farther along because we've gone through several here in West Virginia. We had a water crisis that made the national news, no drinking water. We also had, you know, snowstorms, downed power lines. We had a -- we had some pretty good experiences to base our planning on but you can't plan for every aspect but you can plan as much as you can foresee in your mind of having to go through this and that as far as getting through a disaster.

The last thing I want to mention is back to the peer counseling question. When we started talking about no funding and the needs and it trickles down to us, Yavonka had the same thing going on. And that's the same concept with peer counseling. Now I feel a little better knowing that we're not the only ones and that she has the same needs we have. So that's my point I wanted to make about peer counseling.

>> Yavonka Archaga: Quickly adding to that in terms of preparing and responding and planning. For example, the shelters, individuals need to have a plan that is they have to go into

the shelters that only plan to be there for X amount of days or a week or so. That's what those transition plans do. When we're in the shelters working with FEMA and the Red Cross, we're working to help get individuals transitioned out.

From the mental health standpoint, there's a lot we have to deal with individuals. Just going out to see their homes or not to see their homes. There's a lot we deal with in that capacity in working with individuals.

When the professionals aren't around. When the professionals are around, they can have -- when -- a lot of peer mentoring occurs. And also, we did sessions particularly for the Deaf community because we got wind that they felt that they weren't getting information or being told information. So we participated in sessions, two sessions, that occurred with the Deaf community to hear what their concerns were, to be sure that we were addressing those on these daily calls that we were having, and making sure that they were properly represented.

>> Lewis Kraus: Ok. That's great. We have I think maybe time for a very quick response to one last question. Can we start sharing best practices and resources through the newly created Partners in Inclusive Disaster Strategies, PIDS?

>> Yavonka Archaga: I can tell you if you guys are dealing with shelters, best practices -- now, working with NCIL, the Red Cross has a Director of Disability Information. She's newly appointed for this storm, Sherry Myers. And one of the things that she brought to the table in collaboration with FEMA and included our Independent Living Center and offered it to all partners to have sessions set up at the table in the shelter and met with the survivors. That went extremely well. I would recommend that if individuals were in shelters, they do it if there's a place to meet in the community, they do it. Because consumers are not telling the same information to different people. And then we're all at the table with the resource that each of us come to the table with to get things done in the more effective manner. That worked extremely well. Out of all the years and all the disasters that I've experienced, that has been awesome.

Another best practice we found was we have daily calls with partners in the State of Louisiana that also included FEMA and the Red Cross and the State Department and community partners and Independent Living Centers. And basically ours was facilitated by the Advocacy Center. We just went off of an agenda and talked about the updates on what's going on from each State Department and what the identified needs are and what emergencies. We can't use emergency in an emergency. Right? But what things needed immediate attention? So we found that to be very beneficial.

The sessions that we had, individuals of particular groups were really good. And just staying in communication with FEMA representatives. I thought that was really good, us having contact, direct contact, with not just one FEMA representative but different FEMA representatives who could work with us at different levels and also with state representatives. So it's collaboration and relationships with FEMA, Red Cross, and the state and the community partners we found to be best practices.

>> Lewis Kraus: And I'm going to say also as a response to the question about best practices, that is the function of this webinar series. So just go back and look -- these are the FEMA Promising Practices. Do go back and look. We've covered lots of different promising practices over the past several years. Go to the archive and see. Maybe there will be something appealing to you or really speak to you and your needs.

All right. Well, 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. You have the contact information for

them up on the screen or you can call your regional ADA Center, 1-800-949-4232 to find out more.

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

We want to thank our speakers today for sharing their time and knowledge with us. I thought it was a wonderful presentation. Thank you all very much.

A reminder to everyone that today's session was recorded and it will be available for viewing next week at [www.adapresentations.org/archives.php](http://www.adapresentations.org/archives.php).

Thank you so much for attending today's session. We look forward to seeing you on December 8 for our next ADA National Network Learning Session, The Perspectives of Building Occupants with Mobility Impairments on Fire Evacuation and Elevators, with the authors of this recent publication from the National Institute of Standards and Technology.

Have a good afternoon, everyone. And thank you to our speakers.

Good day.