

REALTIME FILE

Pacific ADA Center
ADA NATIONAL NETWORK LEARNING SESSION:
WE ALL WANT DISABILITY INCLUSION IN
EMERGENCY MANAGEMENT – NEW RESEARCH ON
WHAT IS ACTUALLY HAPPENING
APRIL 11, 2019

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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 on behalf of the ADA National Network. The ADA National Network is made up of 10 regional centers 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.

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I do want to remind you that the webinar is being recorded and will be able to be accessed on www.adapresentations.org in the archive section next week.

This is the fifth 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 series topics 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. Upcoming sessions are available 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, and those notices go out two to three weeks before the next webinar and open that webinar to registration.

You can follow along on 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.

At the conclusion of today's session there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area in this webinar platform. The speaker and I will address them at the end of the session, so feel free to submit them as they come to your mind during the presentation. To do that, to submit your questions, type them in the chat area text box as shown on the screen, or if you're using keyboard, press control m and enter the text in the chat area. If you are listening by phone and not logged into the webinar, you may ask your questions by e-mailing them to adatech@adapacific.org.

If you're having any technical difficulties during the webinar, send a private chat message to us by double clicking on Pacific ADA Center in the participant list. When that tab shows up in your chat panel, type your comment in and enter. If you're using keyboards, you can find us by hitting the F6 button, arrow up or down to locate Pacific ADA Center, and select to send the message. You can also send us a technical assistance issue at our e-mail at adatech@adapacific.org or you can call us at 1-510-285-5600.

Today's ADA National Network Learning Session is titled, *We All Want Disability Inclusion in Emergency Management - New Research on What is Actually Happening*. This webinar will review findings from new research conducted by New York University and the Pacific ADA Center on what local emergency managers in Federal Region IX say they have done and can do to include people with disabilities in emergency planning, response, recovery, and mitigation. Crucial information about disability inclusion in emergency management and the structural needs of local offices to achieve this was discovered.

Today's speaker is Robyn Gershon, a Clinical Professor and researcher at the College of Global Public Health at New York University. She developed and teaches three asynchronous online disaster courses, the most recent on healthcare disaster management. Dr. Gershon's research focus on barriers and facilitators to disaster preparedness, especially with respect to vulnerable populations and essential workers,

including the healthcare and public health workforce.

Dr. Gershon's "World Trade Center Evacuation Study" helped lead the first changes in the New York City high-rise fire safety codes in more than 30 years. One of her most recent studies, "Mass Fatality Preparedness in the U.S.," was the first national study on the operational capabilities and readiness for the management of mass fatalities within the U.S. Along with her colleague, Lewis Kraus of the Pacific ADA Center, she conducted a large national study on disaster preparedness for people with disabilities and their personal assistants. They are currently conducting a study to determine the degree to which the needs of people with disabilities are addressed in local emergency management, FEMA Region IX, disaster planning and response activity. That is the topic of today's session.

Robyn, I will now turn it over you.

>> Robyn Gershon: Ok. Thank you so much, Lewis. I'm hoping that you can hear me perfectly fine.

>> Lewis Kraus: Yes, you're fine.

>> Robyn Gershon: Thank you. And welcome to all of you. It's a pleasure for me to be here today. I'm delighted to tell you a little bit about a study that just was very recently concluded.

Today what I'd like to do is first acknowledge my wonderful co-investigator, Lewis Kraus, and our two wonderful assistants on this project, as well as the important funding resource that led us to do this important work.

Here's a little overview of today's webinar. We'll talk about the OEM role and responsibilities, review why it is important to know if OEM are prepared, and we'll then go right into our data and then wrap up with an application of the findings.

These are some of our learning objectives for today. Quite simple: To determine if local OEMs understand and carry out their responsibilities under the ADA; to list the items that we use to measure OEM preparedness; and then we'll hopefully discuss strategies for improvement.

Today we'd like to be guided by these four underlying questions. What are the roles and responsibilities of OEM? Why is it important for us to know if they are ready or not? What types of information can help us answer this question? How can this information on OEM readiness be helpful to us?

We'll take a quick look at Offices of Emergency Management. These are agencies at the local or state level that are responsible for planning, responding, and recovering to disasters, also to some degree for mitigation. They can vary in size greatly from a simple one-person operation to very large operations with well over 200 professionals. For instance, in New York City -- on this next slide I put a little picture. It's a little blurry. This is the best picture I could find. This is the watch center. And this is operationally 24/7 with several people, some of whom were deployed from agencies in New York City such as fire and police. I visited this center recently. I was really amazed at the amount of data that they have to constantly be screening, including all forms of social media. It was actually pretty exciting to see.

Here on the next slide, which an easier picture to see, this is their main operations floor when it's facing operationalized, activated. This is just one tiny corner of this huge space. This was operationalized when this picture was taken in 2012 Hurricane Sandy. And this is where they have seating and desks appointed for almost every agency imaginable in New York City. It's also quite interesting to see. But many, many other places are, of

course, much smaller than this.

Now, as we all know, all disasters start locally. We go up to the state and then if necessary we go up to federal level. And that's exactly how it works for OEM.

So, what exactly are the roles and responsibilities of local emergency managers? It's quite straight forward. They have to manage resources both before and during and even after a major disaster or emergency event. They have to conduct activities related to their key components of emergency management. And they have to coordinate with all partners in the emergency management process. It sounds pretty straight forward. It's actually pretty complex.

The authority to do this work comes to them through the national response framework. Here I've put up a photo of the 3rd Edition 2016. This is a document that is the guide for how the U.S. responds to all types of disasters. It is scalable, flexible, and adaptable and builds upon a national incident management shift in this ordinance. It includes not only agencies, government authorities, but also the private sector and the voluntary sectors.

So, here in this document, as in other places, DHS and with FEMA, they talk about the whole community. They talk about the whole community meaning they want everyone in the community to be prepared. Including the general public, of course.

Now, OEM also has responsibilities under Title II of the ADA. Under Title II, all emergency programs, services, activities, and facilities must be accessible to people with disabilities. And this requirement not only applies to all of their activities and services, but it applies to all thirty parties that are involved such as the American Red Cross and other private nonprofit organizations, as well as the faith-based sector.

Other responsibilities under Title II include the fact that generally they may not use eligibility criteria to screen out people with disabilities. They also must make modest and reasonable modifications to all of their policies, practices, and procedures when necessary in order to avoid discriminating against people with disabilities. And, furthermore, they must take steps to ensure effective communication for people with disabilities.

Now, when we talk about people with disabilities we have to consider, of course, that they also are included in access and functional needs inclusion criteria. Here on this slide I've put a list of some of these other groups. The list includes people not only with disabilities but people with chronic conditions or injuries, people with limited English proficiency, older adults, children, people with low income or homeless, people who have transportation disadvantages, and pregnant women.

Now, these are large responsibilities and serious responsibilities, but the OEM are aided in this work by the FEMA Office of Disability Integration and Coordination, ODIC. This was established in 2010. And basically, here they're saying we will use all kinds of strategies to integrate and coordinate emergency management inclusiveness for people with access and functional needs. They work in the 10 federal regions across the U.S. And they're responsible for ensuring that access and functional needs and requirements of people with disabilities are being properly addressed in all aspects of emergency preparedness.

I recently took a look at the FEMA 2018-2022 Strategic Plan again. And I was struck, again, thinking about the whole community. Here in Strategic Goal 1, they spelled out quite clearly, and I thought quite, actually, in a moving kind of way because they're talking about building a culture of preparedness. This is a buzz word in the area that I work in, in disaster

preparedness. We're talking more and more about a culture of preparedness and how to measure it and how does the culture of preparedness translate into a climate of preparedness. And FEMA states everyone should be prepared when disaster strikes. And what they are saying is here that general public, including people with disabilities, have to be involved. And FEMA is now asking people to please be prepared to be on [Inaudible] for at least every two hours. And interestingly enough, for hospitals it is now 96 hours. So quite an extended time period.

We now come to our second underlying question. And that is, Why is it important for us to know if OEMs are ready or not? We know what their roles and responsibilities are. They're quite extensive in some ways but let's find out why it's important for us to know if they are ready.

This is the mantra for us in the disaster preparedness world. It's all about morbidity, mortality and cost. Disasters results and increased deaths, increased injury or disease, and infrastructure and response costs, huge costs associated in every which way imaginable. And this is why it's important for us to know because preparedness -- we know, we actually have data on this -- leads to better response and quicker recovery and supports, resiliency of the community.

Now, another important reason for us to want to know about OEM and whether or not they are ready for people with disabilities is because the population of people living with a disability is large and growing. Here is some data. I believe this is the 2017 the ADA report that came out on the disability statistics. You can see these increases depending on what study was looking at, what data they are using, the inclusion criteria. It seems to be an estimated 55 to 60 million Americans are now living with one or more disabilities.

Here is another chart, some one out of four to one out of five people. I think we're in that range, 50 to 60 million people. And you can see here the proportions by different categories of disabilities. It's a huge number of people.

Interestingly, it's going to be growing because of the aging baby boomer population. As the population ages in older people are more at risk for a disability-associated problem as well as a whole host of chronic mobility issues and coordinating and chronic diseases this population is very much growing. From 46 million people today who are aged 65 and older, we're predicted to have 98 million by 2060 who are 65 years and older. Right now 65 and older are only 15% of the population. But by 2060, they will be 24% of the population. So this is why we need to be ready.

Also, it's terribly important as well, as I'm sure most of you are well aware of, we've had major and converging trends that are increasing the risk of disasters. I've just put up a very short list here. The list is actually very, very long, but there is no doubt that disasters are increasing in occurrence in certain areas and definitely wherever they are occurring, they are increasing in severity. A lot of this is being driven by global climate change and certainly severe winter weather, wildfires, can all be attributed as part of that.

We also have this growing risk, growing urbanization. Nowadays we have roughly -- I guess it's 55% of the population that lives in urban areas. But by 2050, it will be about 70%. A lot of these people live in coastal urban areas. And there is a movement towards coastal areas in spite of these horrific storms that we've been having. So, we have people in dense areas, high-risk areas, and we also have a whole host of other problems including the rapid spread of pathogens and the very complex critical infrastructure that we are all depending upon. So if one piece goes down a whole host of other interconnected, critical

infrastructure can go down.

Now, I put up this slide. This data comes from the Center for Research on the Epidemiology of Disasters, CRED. I put the links on the slide notes to all of these websites I'll be using here. This is a particularly good one. They keep a really excellent data. They collect it from multiple sources and what they have found is that since the 1960s, at least, we have excellent data on where these disasters are occurring. Some people may say, oh, well, we have more disasters because we have better reporting. But in fact, definitely since the 1960s, we've had excellent data reporting; so we know these data are fairly accurate. And the trends are ever upward. Given any one year, you may have more or less in any one year, but the trends are up and they're up for these climate logical, hydrological and meteorological events: flooding, extreme weather, droughts, extreme temperature, and, of course, wildfires. So, we're seeing that trend for sure.

Unfortunately, the U.S. is one of the top five nations in terms of disaster occurrences. We are just behind China now, along with India, Philippines, and Indonesia. We comprise the top five countries. We've been in that list for several years now. We've actually moved up to the number two spot within the past couple of years; lists a range of reasons: geologically, geographically, people living on the coast. We just have a lot of -- we, of course, have a lot of [Indiscernible] infrastructure.

Also unfortunately, there is no single area in the U.S. that's spared. Every single state has had major disasters. Certainly, every single FEMA region. This is just a slide that's showing some of the ones in 2018 alone.

For instance, this is 2018, but in 2017, we had 69 major Presidential Disaster Declarations these includes hurricanes watch as Maria in Puerto Rico, which has 3,000 deaths. We also had that year tornado, severe weather, volcanoes, wildfires. Altogether in 2017 we had about 10,000 natural disaster deaths and about \$300 billion in losses.

We also had, interestingly enough, over 100 man-made events including 13 terrorist attacks. And the death toll from those man-made events was about 3,000 deaths and about \$6 billion in losses.

Now, in 2018, the slide I'm showing here, we had 59 major Presidential Disaster Declarations including three of the world's most costliest disasters. These included the California camp fire which started as an urban firestorm in the town of Paradise that had 86 deaths. We had Hurricane Michael in Florida with 60 deaths. That was the third strongest you are cane in U.S. history. We also had Hurricane Florence with 51 deaths. So far in April of 2019, we have had five major Presidential Disaster Declarations. And, of course, we're nowhere near hurricane season yet.

Now, very interesting to me for a number of reasons is the trend, of course, for increased risk from infectious disease outbreaks. This is another of these excellent websites. This is called healthmap.org. It's a free website. It keeps real-time, daily reporting of all the outbreaks in the whole world. I took a snapshot of this particular week in 2017. In that one-week period alone there were 721 alerts just in that one week of these outbreaks.

These are some of the risk factors for the increasing incidents of bio-events, as they're referred to. Again, human population growth. We're encroaching into wildlife areas. That helps facilitate to zoonotic transmission. Again, increased urbanization, travel, climate change, increased vector-borne diseases, and certainly not to be forgotten, substandard public health and healthcare systems throughout the world. That's actually what's behind the outbreak in Madagascar, recent one with quite a few deaths. We also have the issue of

declining vaccination rates and overuse of antibiotics.

And these are just some of the more than 85 emerging pathogens in recent history, brand new ones, that have been identified, brand new to the population. We also have the threat of re-emerging pathogens. Right now in New York City we're having a very serious measles outbreak. I hear it's spreading to other states as well.

Costs are a big concern. These are definitely rising. This is just a little graphic showing some of the really expensive responses in loss of built infrastructure from the recent disasters over the past decade or so. That big spike that's seen for 2011, the \$440 billion in losses, was caused by the great East Japan disaster, which was the earthquake, the Tsunami, and the nuclear meltdown. But in 2017, we had \$306 billion in losses in the U.S. alone. These numbers are not supportable.

I read something interesting recently that said in the past decade, across the world, it's been estimated as \$1 trillion in losses. So, this is real money. These are real resources that could be spent on many other things. That is a big concern.

And here's just a slide, a snapshot, for you to see the 2018 billion-dollar weather and climate disasters in the U.S. As you can see, they are pretty much all over the map.

One other issue that arises from these disasters is the internal displacement of people. Their homes have been destroyed. They need to get away from their communities and they're traveling. Usually it's not across international borders. It's within their own country's borders.

For instance, in 2017, because of the three major Hurricanes Harvey, Irma, and Maria, we displaced over three million Americans because of those storms. And they all happened within one month. So, this puts enormous pressure on OEM who, of course, are heavily involved with finding housing and resources for these displaced people.

The only bright spot in terms of the disaster trends is this slide I'm showing, that the annual death rate has gone down over the past decades that's because of better response. That's because of OEM. That's because of the work of the Red Cross, Doctors Without Borders, the work of Partners in Health, the work of USAID, the work that all the ADA Centers are doing. It's everyone, the whole community, coming together to prepare better and to respond better. And because of that, even though the costs are very high because of the built infrastructure, we, at least, are saving lives. So that is a bright spot.

A very important question for us is to find out if people with disabilities are prepared, are any people in general prepared for disasters. The few studies -- and there are surprisingly few studies on this -- that is the individual or family-level preparedness in America. The few points of data that we have come to us mainly through public opinion polls that use population-based calls. Now they're calling it [Indiscernible] to cell phones but for a long time they were to landlines. Anyway, they call people and ask them three, four, five questions. Do you have a go-bag? Do you have an emergency list? Do you know where your nearest shelter is? They ask those kinds of things.

It's very hard to really get a very good handle of whether or not people in the U.S. are prepared, including people with disabilities. To help address the data gap in 2011, Lewis Kraus and myself conducted a study that was about 250 people with disabilities who also were receiving personal assistance help. We developed a seven-item preparedness plan and checklist. And this is what we found. Now, this was back in 2011, so we have to keep in mind that this was quite a while ago.

47% had an emergency plan. Two-thirds of people with a plan had included a PA in

that plan. 10% had included none of their PAs in their plan. And the one who is did not include the PA said things that were kind of disturbing. They said a PA will be busy tending to the needs of their own family members or "My PA is just not that dependable" and importantly, and very well may be the case, "My PA may not be with me when the emergency occurs." Now, this was a U.S. sample of people, throughout the U.S., a convenient sample.

The checklist, in addition to emergency plans, has these other items on it. 35% had an evacuation plan. 35% had an emergency contact list. 32% had emergency supplies available at home. 29% could communicate with their PA in an emergency. 28% had a go-bag ready. And 26% had backup plans for their PA.

If we were to give the range of the score of this checklist with 0 to 7, the average score was 2.3. If they were to get a grade it would be about a 33% grade.

Our conclusion from the 2011 study was that people who had a plan, through analysis, we found that people who had a plan and had engaged the PA in the plan had higher emergency preparedness scores on the checklist. And people who lived through a disaster before were also significantly more likely to have a higher score. So, that seems to suggest that people with disaster experience are more likely to be prepared.

A more recent study that I conducted in San Francisco when I was out there at UCSF, from 2014. This was a qualitative study of 50 elderly home care recipients. So, these were extremely vulnerable people. Again, I developed a preparedness checklist. This had 13 items on it. The mean score on this checklist was 4.7 out of 13. So the max score was 13. The mean score was 4. Again, about a 35%, 40% score.

And some of the things -- I'm just putting up some of the items here, in the interest of time. Only 56% had extra medications on hand. 44% had backup power for the powered equipment they use. 38% had made backup plans for their home care aid. 26% had plans for transportation. And 19% had someone in their building that could help them evacuate if the elevator was not working. Interestingly, 70% had extra supplies on hand for their pets.

So, since this was qualitative, we were very interested to learn about the factors that influenced their preparedness. We found a lack of self-efficacy. They did not feel that they could do the things they needed to do to prepare. As one person said, "I can't do those preparedness things; the government should help me." Their risk awareness was high, but unfortunately a lot of them had a sense of stablism. As one person said, "I've lived a full life. I'm ready to go." A lot of them told us, well, I'm going to die soon anyway so I don't need to prepare. The sense of community was quite low. I put some quote here, somebody said, "They don't really care. I've been sick right in here and no one came and knocked on the door. That's just the way it is."

And actually in San Francisco, which is undergoing a transformational shift with many, many millennials moving into areas where there had been older San Francisco residents and the buildings are getting mixed. So even in the small mid-rise or walkup places, on some floors there are these millennials and older people on the same floor, even home care patients on the same floor, and they're not communicating, let's put it that way.

Also in the sample was a lack of trust in authorities. As one person said, you can't depend on the police, the fire, the Army or the National Guard. You can't depend on the city or county. So these are the reasons why their score on that checklist was so low.

And finally, we have some very interesting data from the 2014 FEMA report, "Preparedness in America" survey. If you haven't seen this, I've put the link here. It's really

quite excellent. I think would appreciate it. Their sample is very large, 2,000 people. And it is population-based. So it's representative, including people with disabilities.

They found that 21% of the U.S. sample were not planning to do any disaster preparation. 21%. 46% said preparedness was not at all on their radar. And some of the barriers to being prepared was cost and not knowing how to prepare.

Now, we can definitely appreciate the lack of resources and the costs because there is some cost involved. It can be costly to some degree. But not knowing, at least not knowing what to do, is hard to understand because there are so many great resources at FEMA, at the Red Cross websites. There are really excellent, excellent checklists and preparedness bags. So that's a little hard to understand.

But anyway, people who felt they were at risk, felt confident that they could do something, were more likely to be prepared according to this FEMA 2014 report.

They found, interestingly, only small differences noted for people with a disability. So, our studies indicate that people with disabilities are no more likely and in some cases less likely to be prepared than people without disabilities.

To recap, it's important to note if OEMs are ready or not because the population is large and growing, disasters are increasing in frequency and severity, some types of disasters, and individual level, family household level preparedness is low.

And finally, the other important reason is because while data on this is very, very sparse, it seems to suggest that there is an increased risk of fatality, perhaps as high as 50% for people who have disabilities. There are some limited studies, for instance, 50% of Katrina fatalities were elderly people over 75. Some other studies have shown that they are definitely at increased risk and maybe as high as 50%. And that is a great concern. It's a disparity we never want to see.

So now we've come to the third underlying question and that is: What type of information can help us answer this question about whether or not they're ready? The way to ask that question and to answer it is to go right to OEM. And that's just what Lewis and I did. We wanted to determine the extent to which ADA requirements have been implemented by local OEM.

The study was conducted, just completed, conducted in the winter of 2018. We developed our own survey instrument with help from our wonderful key stakeholders. We developed a confidential web-based survey. We used FEMA Region IX, California, Nevada, Arizona, Hawaii, and the Pacific Islands. It was a confidential questionnaire. We used a multi-modal recruitment strategy. And we had about 75 respondents. And the questions were all aimed at inclusiveness at the four key disaster phases: mitigation, planning, response, and recovery. After pilot testing to make sure that it was understandable and readable and easy to get through, we finally tied it out at about 15 to 20 minutes and only had 40 items. Then we conducted mainly descriptive, statistics, and factor analysis of scale.

This is what we found. Most of the respondents were populations of \$100,000 to \$500,000, had very small, typically just themselves or two to five people. About half of them reported one major disaster, at least one major disaster event, in their jurisdiction in the last five years.

35% had access to estimates of the number of people with disabilities in their jurisdiction, but only 1/3 of those with these estimates used them in their planning. 55% maintained up-to-date lists of local disability agencies and caregiver groups.

Three-quarters prepare plans that address the needs of people with disabilities. 52% had an ADA coordinator in anywhere jurisdiction. And about 50% involve the coordinator in their plan preparation. Roughly 54% involved disability organizations in their plan. And 52% had detailed Operating Procedures for people with disabilities in their plan to make sure that they were in compliance with the ADA, 52%.

Now, we're looking at the training results here. While quite high at 69% who were training all of their staff and volunteers on their plan, only 41% trained them on identifying the needs of people with disabilities, 49% trained them on meeting those needs, and 39% trained them on the requirements under ADA. That's important to point out. 39% trained their staff and volunteers on the requirements under ADA.

When we asked them questions about their role, are they clear about their role, a large proportion, 78%, stated that OEM managers are clear about their role and responsibilities for providing equal access but only 36% said that they have qualified staff and other resources that would enable them to meet responsibilities.

We asked about communications. We asked quite a few number of questions on this. These were quite good. The types of emergency notifications, they said -- the proportions were quite high: 82% used closed captioning, 82% social media, 80% reverse 911, 68% verbal description of evacuation zones and road closures, and 68% said they had American Sign Language interpreters at press conferences.

However, in terms of testing their emergency warning systems with people with disabilities, that was quite low. Only 28% test it with people with vision disabilities, 33% with hearing disabilities, 25% with mobility disabilities, 13% with cognitive disabilities, and only 9% with mental health disabilities. So, they have a lot of these resources but they're not testing them.

In terms of having MOUs in hand for providing necessary services that assure access: 89% had shelter facility operations, accessible shelter facility operations. 53% had accessible transportation MOUs 53%, again had registration staff that had special customer service training for people with disabilities. And 52% said they provided sign language interpreters or had the MOUs for sign language interpreters, at the shelter.

This was an interesting item we added. I think Lewis was the one that recommended this item about what did they know about training on the ADA requirements with respect to a local first responder. And to their knowledge, 52% said that local first responders typically receive training for the disaster needs of people with disabilities and only 40% thought the local responders received training on the requirements under ADA. This is an area that might need further exploration about what the responders know.

Now, we looked -- we had quite a few number of questions on accessible features of mass care shelters and disaster assistance shelters. And these were generally quite good. 86% said yes, ramps were available. There were no barriers to wheelchairs, 76% reported on that. 70% said they used the ADA Checklist of Existing Facilities for restroom accessibility. 67% said they had emergency generators. 58% had quiet rooms available. 50% said they had immediate access to food and refrigerated medicine. 42% had oxygen availability. And 35% have alternative forms of communication.

In terms of service animals, which is quite good, 84% said they had policy modifications to allow these animals. And 71% said they even provided relief areas for these animals.

In terms of allowing personal assistants, only 67% said they had policies to allow the

PA to visit and do tasks.

25% said they tend to shelter people with disabilities in medical shelters even if they do not have a medical condition that requires it.

It seems that 60% said their staff and volunteers are trained and monitored to assure that they provide assistance, safe and appropriate assistance, with EDL and wheelchair transfers if necessary.

We added several questions that had to do with local employers as a special interest of mine. 24% said that they did coordinate with local employers to make sure that they had good evacuation procedures in place for people with disabilities whether it was their employees or visitors or customers.

We asked the same question of high-rise building managers. Only 29% reported coordination with high-rise building managers for the purpose.

This was a very important set of questions about involving people with disabilities in the process. 45% said they actively involve people with disabilities in drills and exercises 28% said they accommodated their engagement through accessible transportation. And 21% said they had sign language interpreters to allow them to participate in the drills and exercises. So, engagement of people from the community with disabilities in their actual drills and exercises was not strong.

Recovery, though, those results were quite encouraging. 70% said that they assisted people with disabilities in helping them obtain information on benefits. 79% said they even provided appropriate equipment that would help them gain access to this info.

Also, the after-action reports, 93% said they are typically prepared. And many said that changes are needed based on them. But only 48% involve people with disabilities in the preparation of the actual reports. And 39% involve people with disabilities in their post-disaster mitigation planning. So those scores were quite low.

So, we developed from all of our items, which is quite a bit of analysis to find a very short, easy-to-use checklist. We've seen all the wonderful checklists out there, the ADA checklist. We've reviewed all of them to actually develop this survey. 11 items held together in a factor analysis, highly correlated with each other. So we kept these 11 items, people involving disability organizations or people with disabilities in plan preparation.

So, this is a measure now, we're developing the measure, the metric, if you will, of how could we measure OEM. There are many measures like that out there. This is a very short and concise and easy to do. It can be used as a quality assurance tool a quality improvement tool, in privacy of the OEM, a person OEM or 200 OEM. It can be used internally as something to check. Because we can see that these items are correlated with some important outcomes.

So here are the first six items involving people with disability coordinations, people with disabilities in the plan involving their local ADA coordinators, have operating procedures, have detailed operating procedures to ensure compliance with the ADA; that they consider the needs of people with disabilities in their evacuation planning, and that they have pre-identified accessible transit and shelters.

And the last five items are here: shelter staff and volunteers are trained and monitored; they consider the needs of people with disabilities who may have to shelter in place at work; accessibility is considered for engaging people with disabilities in drills, so they help make it accessible for those people; and that they ensure proper equipment is available to ensure access to benefit info; and finally, that they work closely with the ADA

coordinator on their preparedness plans: So those are the 11 items.

And our score, basically the mean score would have given this sample score of about 50%. It's a little bit higher than what we've seen for individuals in their preparedness planning. 50% is the score, and it's a score that we can improve upon.

We did find that the high score coordinates with collaboration efforts. It also correlates with managers who are clear about their roles it correlates are qualified staff. And it correlates with engaging people with disabilities.

One of the questions we had on the survey: What do you think you need to have improvements for ADA compliance? 61% said they need more training on the ADA requirements 61% again said they need better community outreach to people with disabilities. 59% said they want more drills involving people with disabilities. 59% again said better communication systems for people with disabilities. 57% said they want more planning with local partners and their volunteer organizations. 56% said they wanted more backup power. And 53% said they needed more accessible transportation.

We asked also how do you want to receive that training. Well, 79% said they would like to attend a two-week Emergency Management Institute training, 43% wanted training by webinars, and 43% said they wanted online courses on this.

When we asked, well, who would you like to be your trainer for this kind of training, 67% said they wanted first responders, 65% said they wanted non-government agencies such as the Red Cross and the disability organizations, 64% wanted the Health Department, 56% said they wanted utilities -- I was a little surprised at that, wanted utilities to provide that training, and 54% said they wanted healthcare or hospital organizations to give them that training.

So, in conclusion, we found suboptimal preparedness of OEM was noted. To my knowledge, and maybe people in the webinar today have other knowledge -- I hope that you'll share it with us -- but I believe that this is the first study. There are a number of limitations to this study. The small size is clearly one of them. We don't have a good handle on the number or the exact contact info for local OEMs through the country. That is a gap. We had to use a multi-modal recruitment strategy, so it was a commune example. And, of course, people can give us socially desirable responses, so it could be biased.

However, I do feel I need to tell that about 200 people started the survey and got pretty far into the survey. It looked like people who really had no knowledge of this topic with one or two dropped out. So, I believe the results we have are probably the most heightened in their concern and engagement in this topic. But that can't be known until the studies are done. I certainly don't want to recommend that we have to do more, although certainly it would be good to do more OEMs in fewer regions.

We also found in our conclusion that the engagement of the disability coordinators and people with disabilities was highly beneficial. And clearly we need more improvements. Definitely there was interest in this sample for more improvements.

And finally, the last question: How can this information be helpful? We think there will be more future directions in this topic. We need increased disability expertise at all levels of disaster preparedness and response, at the individual level all the way up to the federal level. We think a national focus is needed.

Now I'm going to turn this back over to Lewis in a second so we can find out what the webinar participants think that these findings may suggest in terms of future directions. So, I'll end it here and say thank you.

Following these slides I've included a number of great resources available. At the Pacific ADA Center.

Thank you.

>> Lewis Kraus: All right. Thank you, Robyn. That was great.

I wanted to let you see -- we just flipped through these last resources quickly. If you don't have the slides, I'm just going to back it up here and sort of let you know that there is a website at our www.adapresentations.org that gives you more detail about emergencies, also this webinar series, as you're familiar with.

On our website we do have checklist that are personal, different ways that individuals can prepare. And then there are also checklists for agencies, like maintaining accessibility and press conference checklist. So these resources are available, and some that Robyn brought up are there for you.

Do go ahead and submit your questions. As we're talking here, we'll start answering some of those questions right away. Also, as Robyn asked, if you have ideas about what these results really indicate, we can use this time also as a way to gather joint ideas about the results.

I wanted to just point out one thing. Back when Robyn was talking about the kinds of preparedness measures that we got, if they have prepared in a variety of different ways, and there were different percentages most of those -- and there were percentages up and down, you know, 40s, 50s, 20s, 80s most of those really in an ideal world should be 100%.

So, this may be obvious to everyone, but I want you to sort of think about these things in terms of, you know, this getting to near 100% or at 100% is where we will be doing the best possible thing that we can in every area about having a local OEM prepared for meeting the needs of people with disabilities and meeting the requirements under the ADA.

All right. Given that, here come some questions. Robyn, here's the first one. And I believe this got answered but it came in mid-stream.

What are the differences of percentages in readiness between those with disabilities and those without? That came in before you answer -- before you answer, Robyn this question came in before the FEMA results which showed how things were pretty equivalent for people without disabilities. But anyway, Robyn, if you have another answer to that.

>> Robyn Gershon: Yes. I believe that what I've seen of these public opinion polls and a couple of small surveys, it's about 40% of the general population has at least the minimal requirement, like a very small list of go-bag, having an emergency contact list, and that sort of thing. And people with disabilities, I believe, are a few percentage points below that.

>> Lewis Kraus: Ok. Great.

Also, let me -- if you go to the www.adapresentations.org right now, of course this happens to be a day when something has fallen through the cracks at our ISP. So, if you get to it, it will say -- your browser may tell you there's a warning. Don't worry. It is fine. You can go through the advanced and say it's ok to take me there. Sorry to give you that detail.

Next question. Most of the emergency management training I attend seems to be focused on the larger communities. Does anyone know of a consortium or group of colleges that focus on this issue? I would like to share ideas and strategies.

Do you have an answer to that one, Robyn?

[No Audible Response]

Robyn, do we still have you?

>> Robyn Gershon: Here I am. I'm sorry. I was muted. I was looking at the questions in the

chatroom.

>> Lewis Kraus: I'm just going to read them off to you.

>> Robyn Gershon: Ok.

>> Lewis Kraus: So, most of the emergency management training I attend seems to be focused on the larger community. Does anyone know of a consortium or group of colleges that focused on this issue? I would like to share ideas and strategies.

>> Robyn Gershon: I have never seen it personally.

>> Lewis Kraus: Yeah. And I think the answer to that really is if you look at this, most of the training should be in the community. I believe that the focus is really trying to make sure that people understand what's going on within their community.

Now, if you're talking about in general understanding about emergency management, I think that FEMA has a whole series of trainings that people can go through that, give you that information.

They used to have a course specifically on those with access and functional needs. They took that down a little while ago to replace it with something new. I don't believe it's up yet, but it should be again soon. There are other local resources or national resources that might have some things available as well. And you might be able to find some of those resources at our website, when it's back available.

Next question.

>> Robyn Gershon: That was a scary message. [Laughter]

>> Lewis Kraus: Yeah. Next question. Is there a way to access a report from the OEM inclusivity study?

>> Robyn Gershon: Yes. We have a publication that is going to be ready for submission in probably two weeks. And before that, there will be a report that will be ready for the agency. Certainly we can make that report available. And we can definitely post the paper as soon as it's done.

>> Lewis Kraus: Right. I would say this study, to the extent that we can navigate the publishing world as well as publicly releasing other report about what the paper might go into. So, there will be a paper in the professional journal that we'll have available and also there might be a way to summarize, explain the things that Robyn just went over.

Also, this webinar will be a way to sort of look back at a report about the study and summarized at the www.adapresentations.org. But the written report will probably be available on our Pacific ADA Center site once we are complete with that report.

>> Robyn Gershon: And what about the survey instrument? Will that be made available on your site?

>> Lewis Kraus: We can discuss that. I don't know what to say about that. We can certainly put it out there if that's an important thing to do.

>> Robyn Gershon: I think people would like to see it.

>> Lewis Kraus: All right. Next question. There's several questions here from this person.

I personally would have preferred a comprehensible measurable recommendation, for example, by next year the people in this group will increase in preparation by X percentage, and more focus on the funding available for addressing this problem. Can small business receive funding for addressing these issues?

And finally: I am aware fire departments will give away smoke detectors for hearing population that can't afford them. Few give away smoke detectors for deaf. Some provide bed shakers but those seem to be only effective if the person is in dead. Can we push for

an effective notification system for both daytime and nighttime?

>> Robyn Gershon: [Inaudible]

>> Lewis Kraus: Yeah. These are good ideas.

>> Robyn Gershon: [Inaudible]

>> Lewis Kraus: Uh-huh. These are good ideas. Let me just say that this research is not suggesting a particular -- you know what the emphasis should be in the next year or whatever it is. So, your first question -- for the people who will take these results and try to deal with them in their local area. But as I pointed out at the beginning, really, all of these OEMs should be at 100%, yes to all of those preparation items that we talked about.

And the funding availability, that's going to be an advocacy issue that somebody's going to have to pick up the ball and deal with with your local, state, and federal representatives because that's where the funding is coming from.

I don't know, Robyn, if you want to add anything.

>> Robyn Gershon: I don't know of any source of funding for small businesses. It's a terrible gap. Large businesses, too, but small businesses, that is really a dreadful gap and I'm not quite sure how that gets addressed.

>> Lewis Kraus: Yeah. There is some ADA-related -- excuse me -- excuse me -- tax credits that small businesses can get, making their businesses accessible. I don't know if it applies directly for emergency management -- or emergency preparedness kinds of things, but I think that's an interesting development. And if anybody knows an answer to that, let us know.

Ok. Let's move to another question. At my institution, management requires the ADA office to notify people with disabilities prior to an emergency drill of any kind. Are we doing our clients a service by providing a warning ahead of time or would it be better to have them participate without prior knowledge?

I can take that one, Robyn. Let me try that one.

When you're doing a drill, there's a few reasons why you would want to be doing a drill. One of them is just to get people to understand basically how to do things. Another thing might be to sort of capture people, like, when they're not prepared and ready to go so that they have to apply what they've learned. So, I think in the first instance, that's kind of what your institution is doing. They're wanting people to be prepared on how to deal with something when it is more of a surprise. There could be another kind of drill that would happen when it is more of a surprise.

Regardless, I think one thing that you're bringing up, which is very important, at institutions and organizations, is to do the preparedness ahead of time within the organization. Does the person with the disability have all the resources that they need? Do they know where to go? Do they have a buddy if necessary within the organization who will deal with any kinds of needs that they have in the event of an emergency? All of those kinds of things need to be worked out with the person with the disability ahead of time so that they understand so everyone understands, what's going to be required if an emergency happens at that building.

So that's kind of the way I would answer that. Robyn, do you have anything else to say about that?

>> Robyn Gershon: I have heard of some buildings, high-rises, doing drills specifically for the person with the disability and their team, the team partners. I think that there's a lot of value in that. Usually it's done more than once in case somebody is missing that day. They

will bring in other people. But for some people they may need a team approach, and so knowing how to use any evacuation systems, I think it's important to do that kind of drilling.

>> Lewis Kraus: And I would re-emphasize again that this is really with the person with the disability being the major decider and describer of what's necessary in that instance.

>> Robyn Gershon: Absolutely.

>> Lewis Kraus: Ok. Next question. Do you know of any funding or grant opportunities for educational institutions to make facilities more accessible? That is your big question. I will tell you that I don't know that there's particular grant opportunities or funding but there is the responsibility. So I think these educational institutions know this and need to prioritize this.

I don't know what else to tell you about that, but that's what is required for them as an institution.

Onward we go. Next question. Can you address the role of advisory groups in inclusion of people with disabilities in emergency management? How can OEMs collaborate with a council of consumers in a meaningful way?

Any thoughts about that?

>> Robyn Gershon: That's a great question. When we've worked with advisory groups from the community, we've had monthly groups, we had an agenda, a purpose, a goal. But I think having almost every sector from the community represented is so important. It took us about a year or more of meeting and getting to know each other. But once we did, it just was fabulous. We really were able to accomplish so much.

And in that case we were working on elderly people living in the community who were living alone. Some of them had disabilities. Some needed home care. But it took us a while to even find all the different groups that should be represented. Once we did, it was well worth the effort and very effective.

>> Lewis Kraus: Let me add that part of the reason we asked the question to emergency managers was for this exact reason. Did they understand or did they have contact with people with disabilities or disability organizations within the area? And you saw that it was 50% or less. So they really didn't make the connection. That is the first step, to know who are the disability organizations in your region. There are a variety of ways to get that from internet searches, to calling your local ADA Center. You can call that 1-800 number and the centers can help you find out who are the disability organizations and make that outreach and get those people involved in your planning advisory groups and your testing groups or your exercise groups. Make sure that that input is there. That's going to really give you the meaningful way that you're talking about. You just have to include those organizations as you would anyone else from the community in developing your plan.

>> Robyn Gershon: That's great.

>> Lewis Kraus: Ok. The next question. Are there programs in the country for using LEAs successfully as access to youth who will transition into the community to share information about disaster preparedness?

Any idea where we might be able to find that information?

LEAs, can you type in what you mean by LEAs so we're using the right -- local education agencies. Ok. I don't have an answer for that.

Robyn, do you have an answer for that?

>> Robyn Gershon: Let me see if I get this straight. These are youth involved with LEAs, how to get them trained so that they can then go back out into the community? Is that what the question is?

>> Lewis Kraus: Yeah. Using LEAs as access to youth who will transition into the community, sharing information about disaster preparedness. I don't know how you would find that out. You would have to talk to each LEA, as far as I can imagine. But maybe somebody else has an answer to this question.

>> Robyn Gershon: I think the Red Cross had some kind of youth training group, at least in New York City. Maybe somebody else here can speak to that. I thought it was a great idea. I also think having emergency preparedness disaster response training in the schools in general is a great idea. At every level, pretty much. That's a great way to get back out into the community. It's a great idea. Just not sure how to affect it.

>> Lewis Kraus: Mm-hmm. Mm-hmm. Ok. Next question. You mentioned politicians would have to be pushed for the funding necessary to address the issue. Have you worked with any that you know of that are interested in pushing for that you can recommend as the ideal gladiator to push the proposal through? [Laughter] That's a great term.

>> Robyn Gershon: It is.

>> Lewis Kraus: Well, just so you understand, the ADA Centers are not advocates -- advocacy agencies. So I wouldn't be able to help with you that. I don't know if Robyn has anybody. But I think you just deal with your local -- I guess the local -- your local --

>> Robyn Gershon: Local representative. I like going to community boards. They seem to really get things going.

Also [Indiscernible] we are really not supposed to get that heavily involved in advocacy. The data is supposed to speak for itself. Right? But it's hard kind of not to. I have noticed at least in New York City going to a local community board sometimes gets things done.

>> Lewis Kraus: Ok. All right. And, the next question. What happens if someone has more than one disability? I use a wheelchair and have vision and hearing impairments also. What if someone's disability is invisible such as autism or TBI?

Ok. So, this is a great question. And it is, again -- if we're talking about the issue for local emergency managers, this is the kind of outreach that needs to get done by emergency managers to the community, to find out what are the particular needs of people with the disability who have different kinds of disabilities, and all of these disabilities, you know, if they're combining, would also have particular needs.

And, for the individual -- because I can't tell from your question if you're asking about the individual or the OEM. For the individual, you have to figure out what it is that you need and be able to express that and make that available for somebody who is going to assist you or is part of your support team, at home, at work, wherever. And there's a variety of help about that at our website with all of those resources, when the website issue gets resolved, hopefully later today.

All right. Let's see. One last question. Can you tell us what changes you push through after 9/11 disaster in regards to disabilities? I heard something about that work you did at the beginning but a few examples of the changes would be awesome.

Do you have something to say about that, Robyn?

>> Robyn Gershon: Well, the one thing that I think made the big difference is I was invited into the New York City Fire Department, very high-level meeting, being held to decide what can be done about high-rise workplaces and what can be done to get everyone out, including people with disabilities. So, of course, I had worked with them very closely on the study from the very beginning of it. I was engaged and involved with them. But when the

study was over, I showed quite a few very interesting bits of data that had to do with people with disabilities being more likely to have injuries that day.

We don't really know completely about the increased risk of fatalities because we didn't have really data on all of the people with who have died. So, to that part it wasn't clear how to get that. But for the people who survived, we knew people with disabilities were at a greater risk for injury, also PTSDs, long-term mental health problems. They really were stressed that day and struggled to get out.

So, anyway, I met with the New York City Fire Department. I went on a weekly basis. I think it was every Wednesday morning for a couple of hours. They were writing the new New York City Emergency Action Plan and then developed the Emergency Action Plan Directors Examination so that every high-rise occupancy would have this new role, not just a fire marshal, but somebody trained on emergency management, someone that could affect a full-on evacuation and do all the training and all of that sort of thing. So, it was a high level. They had to take it pretty seriously to get lots of training, to get that role.

So, meeting with them, as they were working on this, they asked me, well, what do you think about that and what do you think about that. So I was able to bring in all of the stuff that we had found. And it was a very extensive survey, lots of data. I'm happy to send some of the publications that came out of that big study and maybe we can post it somewhere, Lewis.

But, eventually they were able to see that they needed a new high-rise, you know, evacuation code, a new high-rise fire safety code. They did write that. They write this new Emergency Action Plan law, and this new action plan [Indiscernible].

And that's how you make change. You have to be at the table. You have to be a trusted source. With the data it helped write that survey. So that's something that's very important here. It led to change.

>> Lewis Kraus: Ok. Here's one more question. I would like to know where I can find resources, more resources, on how to manage emergencies for people with disabilities that don't understand what an emergency is and how to prepare them.

This is from a parent. And I will say a couple of things. One is, you should go look at the www.adapresentations.org, our website, and look in the archives. It was in February we had a webinar about Feeling Safe Being Safe which was a program, a preparedness program, developed by people with developmental disabilities and for people -- for everyone but also for people with developmental disabilities. It might be a good resource for you to look at and review.

Other than that, I would say that this is all about trying to figure out and determine the needs and try to work with him through all of those checklists about what do you think you need for this and that and just work with him on however your communication is.

>> Robyn Gershon: Yeah. There are all kinds of emergencies -- water is out, power is out, there's a fire, there's smaller scale emergencies but still serious and can lead to fatalities. So we have to be prepared for the small and the large.

>> Lewis Kraus: All right. I think -- thank you very much. We realize that many of you may still have questions for Robyn and apologize if you didn't get a chance to ask your question. But you can also contact your regional ADA Center with general ADA questions at 1-800-949-4232.

You will 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 want to

demonstrate to our funder the importance of what we're doing.

We want to thank Robyn today for sharing her time and knowledge with us.

A reminder that today's session was recorded and will be available for viewing next week at the www.adapresentations.org/archives.php.

On our next webinar, May 9, a representative from the International Code Council will look at how accessibility fits in the design and construction of storm shelters for protection from tornadoes and hurricanes. We hope you can join us. Watch your e-mail two to three weeks ahead of time for the announcement of the opening of registration for that webinar.

Thank you, again, for attending today's session. Thank you, again, Robyn for today. And with that, everyone, have a good rest of your day.