

REALTIME FILE

Pacific ADA Center  
GETTING IT RIGHT - AN AFTER ACTION REPORT ON  
MAJOR DISASTERS OF 2018-18  
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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 you by the Pacific ADA Center on behalf of the ADA National Network. 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.

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And I do want you to note that the webinar is being recorded and will be able to be accessed on the ADA presentations website at the archive tab next week, [www.adapresentations.org/archives.php](http://www.adapresentations.org/archives.php).

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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 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 cover emergency preparedness in disaster response, recovery and mitigation, as well as reasonable accessibility and accommodation issues under the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, ADA, and other relevant laws. Upcoming sessions are available at [www.adapresentations.org/schedule.php](http://www.adapresentations.org/schedule.php).

These monthly webinars occur on the second Thursday of the month at 2:30 Eastern time, 1:30 Central time 12: 30 Mountain time and 11:30 a.m. Pacific time. By being here you are on the list to receive notices for future webinars in this series. 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](http://www.adapresentations.org/schedule.php) web page.

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 within the webinar platform. The speakers and I will address them at the end of the session. So feel free to submit them as they come to your mind during the presentation. To do that, you can type and submit the questions in the chat area text box or you can press control m and enter 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](mailto:adatech@adapacific.org). That is [adatech@adapacific.org](mailto:adatech@adapacific.org).

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Today's session is entitled Getting It Right - An After Action Report on Major Disasters of 2017-18. This webinar is a discussion and review of the Partnership for Inclusive Disaster Strategies After Action Report called "Getting it Wrong: An Indictment with a Blueprint for Getting it Right; Disability Rights, Obligations and Responsibilities Before During and After Disasters," which was published in May of 2018.

This report is an unvarnished account of the results of poor planning and failed execution throughout the 2017 and `18 disasters as reported by people with disabilities and others with firsthand knowledge. The report also documents promising and good practices that can be refined, customized and replicated. Most importantly it contains recommendations for getting it right before the next disasters strike.

Today's speakers to take us through that are Marcie Roth, who is the CEO of the Partnership for Inclusive Disaster Strategies. Marcie's primary focus is on capacity building for community leaders and emergency management stakeholders, working together to prepare for emergencies and recover from disasters by providing tools, resources, training and technical assistance.

Previously Marcie was appointed by President Obama to the U.S. Department of Homeland Security Federal Emergency Management Agency, FEMA from 2009 to 2017. She served as the Senior Advisor to the administrator and congressionally mandated Disability Coordinator for the agency. While at FEMA she established the Office of Disability Integration and Coordination, the ODIC, serving as its director. Under her leadership, ODIC led national transformation towards integrating the access and functional needs of the whole community throughout emergency preparedness and disaster response, recovery and mitigation.

Melissa Marshall is the Policy Director of Partnership for Inclusive Disaster Strategies. She is also the Principal of the Melissa Marshall Disability Consulting. Melissa has had a lifelong career in disability rights. Her most recent efforts have focused on the legal rights of children and adults with disabilities before, during, and after disasters. Throughout the 2017-18 disasters, Ms. Marshall managed the Partnership for Inclusive Disaster Strategies Hotline and provided the Partnership with both policy expertise and operations coordination. Previously she was the founding Executive Director of the Disabilities Network of Eastern Connecticut, a Center for Independent Living. She was the first Director of the Connecticut Protection and Advocacy for Protection & Advocacy for Individuals with Mental Illness program, and the Executive Director of the Connecticut Business Leadership Network.

June Isaacson Kailes has a disability policy consulting practice and is the Associate Director of the Harris Family Center for Disability and Health Policy at Western University of Health Sciences in Pomona, California. June's consulting and publications focus on building disability actionable competencies in the worlds of healthcare and emergency management to ensure people with disabilities and others with access and functional needs are integrated and included in service delivery processes, procedures, protocols, policies, and training. She has worked nationally with FEMA, the Centers for Disease Control, the Department of Homeland Security, and Health and Human Services on policy, planning, and training issues.

In the emergency management world, June is a pioneer, leader and innovator. Examples of her impact and influence include: Researching and writing "Southern California Wildfires After Action Report," developing inclusive emergency management plans that close service gaps, prevent civil rights violations, and emphasize and incorporate standard operating procedures, field operation guides, just-in-time checklists and exercises promoting and moving the emergency management world from the vague special needs focus to operationalizing an access and functional needs approach to planning and response, originating and working with the State of California to adopt and implement the use of Functional Assessment Service Team, or FAST, and documenting the critical need to reevaluate the use of emergency registries in order to avoid symbolic planning.

All right. I will turn it over to you, Marcie, Melissa, and June.

>> Marcie Roth: Thank you very much, Lewis. We appreciate the opportunity. Just want to do a quick sound check and make sure we are good to go.

>> Lewis Kraus: You are good.

>> Marcie Roth: Thank you very much. We truly appreciate the Pacific ADA Center and the National Network for your ongoing series and for the opportunity to speak with folks today

about our After Action Report.

I want to say hello to everybody from San Juan. I've had the great opportunity while I've been down here to catch up with a number of the disability community leaders doing such incredibly important work here in Puerto Rico. I can only stay with you all for first part of the session today because I do have other commitments here in Puerto Rico.

We will focus on three learning objectives -- Lewis, if would please move to the first slide -- Understanding the effect of non-compliance on people with disabilities during the recent disasters; understanding all of the complex circumstance that have contributed to disproportion impact for people with disabilities; and being aware of the recommendations that we made in the After Action Report for getting it right and the valuable input from key informants from across the country on the recommendations that we've put forth.

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The Partnership for Inclusive Disaster Strategies, which is about a year and a half old, is an organization that essentially focuses on advocacy, community engagement, training, technical assistance, and disaster services, always in support of community leaders, always supporting the guidance and strength of local disability organizations and working in support of the local disability leaders before, during, and after disasters to facilitate equal access, inclusion, and independence to benefit the whole community and the ability for local communities to be resilient in the face of and in recovery from disasters.

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We offer a variety of services and we will be drawing from many of those today as we talk with you about the After Action Report and our findings.

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Much of our work is driven by the Post-Katrina Emergency Management Reform Act and the imperative included in the PKEMRA that created the national preparedness goal and the National Preparedness System. And in the National Preparedness Goal it was very clearly described that in order to eradicate the institutional barriers that make it so difficult for people with disabilities to receive equal access before, during, and after disasters, that we needed to ensure in emergency management that program services, goods, activities, facilities, privileges, advantages, and accommodations are provided with equal accessibility to community members who may be impacted in disasters.

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In the National Preparedness System, it was noted that it was extremely important that while there may be some exceptions or waivers in a disaster to rules and regulations, that there are no waivers exceptions, exemptions, to human and civil rights laws and that people with disabilities must continue to receive the equal access to programs, physical access and effective communication access that the law requires regardless of the disaster.

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2017 was an especially notable year for disasters. So I've shared a map that comes from NOAA, which is a depiction of the \$16 billion weather and climate disasters across the United States in 2017. It was an especially bad year. And as bad as it was for the whole community, it was particularly bad for people with disabilities. In fact, we know that in FEMA's recent After Action Report they described that 47 million people were impacted by the disasters from August through December of 2017. And given the CDC's description, 22% of the population, U.S. population, are people with disabilities, we know that of those 47 million people who were impacted, the likelihood is somewhere between 9 million and 10 million of

them were, in fact, people with disabilities.

We also know that for many people with disabilities, the failure to provide the kind of health safety and independent support that people needed resulted in the kinds of health crises that, unfortunately in many cases, ended in death. Many others, unfortunately, were institutionalized. And there are many people today who still have not had the opportunity to begin to recover from the disasters.

In fact, earlier today there was an update on the loss of life in Puerto Rico. There was previously a report that a lot of life in Puerto Rico was 64 people. We know because of the work that we've done that those numbers were much higher. As it turns out, Harvard did a study that identified the loss of life was probably somewhere in excess of 4,000 people. And earlier today the government of Puerto Rico said that they can confirm that there were almost 2,000 people who lost their lives and further study continues. And this is just in Puerto Rico.

We also know that in Texas, for example, there are 35,000 households that are homeowners and 50,000 households that are renters who are under-housed or homeless as we speak. So over 200,000 people who have not been able to restore the level of housing that they had previously been in before the disaster.

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Among the work that we've done with the partnership, we have been very excited and really impressed by the hard work of disability organizations across Puerto Rico who have come together and established the Puerto Rico Disability Community Relief Network. This collaboration is one that we've seen building in a number of other states and territories but the Puerto Rico Disability Community Relief Network has really been one of those promising practices that we've written about in the After Action Report.

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This Community of Relief Network has come together to provide: Advocacy, capacity building, dissemination of evidence-based approaches, research and evaluation, and with a focus on preparedness, planning, response, recovery and mitigation. And this is, again, one of those promising practice that in our After Action Report we point to as one of the fundamental elements of what is going to move us to better outcomes not only for people with disabilities but for the whole community.

So what is an After Action Report and why did we do it?

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There are often After Action Reports developed and disseminated after events that are outside of the norm. And there have been many After Action Reports written after disasters. It became very clear to us that the stories of our key informants needed to be told in a way that cuts through all of the varnish that is often applied to reporting and that it was our intent to deliver not only a very honest look at what went wrong but, as well to provide the kinds of recommendations that could drive real change to improve real outcomes.

June Kailes, Melissa Marshall, and I worked together for many, many, many hours over many days and weeks to put out the first editions of this After Action Report and we are now in the process of looking for funding for the one year later look at what has happened. We're very grateful to Portlight and to many generous donors who have made it possible for us to provide this document.

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Our After Action Report brought together data from our Disaster Hotline, which received well over 3,200 calls. Information was also gleaned from our daily stakeholder

teleconferences which began essentially as soon as Hurricane Harvey struck and continued on a daily basis for many months and still continue on a weekly basis. We also utilized Department of Homeland Security listening sessions, congressional correspondence and testimony, and many media reports.

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What we found -- unfortunately, we were not surprised but we were discouraged to discover that decades of data and information from previous disasters had not been applied. And throughout the After Action Report we share examples of this.

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We were not surprised but disheartened to see that the lack of equal access had a particularly big impact on individuals who are -- who identified as being multiply marginalized or people who, might in addition to disability, might be people of color, might be women or immigrants, people who are LGBTQ. It was reinforced to us that individuals without documentation were especially impacted by the lack of equal access.

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Also among our findings we recognized there has been a continual reliance on disability organizations as the first stop a resource after other resources had been identified. And we've come to refer to disability organizations as the provider of first resort. And unfortunately that is almost never inclusive of any sort of funding or financial assistance for providing critical assistance for life-saving and life-sustaining needs.

We have also noted that the constant use of volunteers and donations has been a primary delivery of the government's approaches to meeting disability civil rights obligations. And we raised some concerns about the use of volunteers and donations as a tool for meeting civil rights obligations and our strong recommendations to look very carefully at whether or not the use of these approaches actually meets the civil rights obligations that the government has associated with their responsibilities under the Rehabilitation Act.

And then finally in our findings we noted that disability organizations had to fill gaps to find people to provide accommodations, to distribute basic food, water, disability equipment and supplies. And much of our work has also been in focusing on making sure that individuals were not unnecessarily -- nobody's necessarily institutionalized -- that people with disabilities are not institutionalized because of a lack of planning and service delivery to give people their equal access to those emergency services.

I am now going to turn this session over to Melissa Marshall who is going to talk about legal obligations. I will not be here for the Q&A but always available and happy to continue the discussion after the meeting. So if there are any particular questions or comments that folks would like to make to me, feel free to reach out. Happy to continue the discussion.

Thank you very much for having me.

>> Melissa Marshall: Thank you. This is Melissa. I'm doing a quick sound check. Can you hear me, Lewis?

>> Lewis Kraus: Yes. You sound great, Melissa.

>> Melissa Marshall: Wonderful.

Again, I want to thank the Pacific ADA Center for making this happen and for supporting the issues that people with disabilities before, during, and after disasters and for doing the great work you do around teaching people about and getting compliance with the Americans with Disabilities Act. I'm an ADA person at heart so it does my heart good to be on this call and to be doing this. So thank you again.

Also, I want to thank all of you that have joined on the call and for taking your time today for this really important issue. So I'm really glad you're all here and I'm really glad we're here.

I'm going to talk for just two slides about legal obligations and then I'm going to turn it over to June Kailes. Then it will come back to me and I'll talk about some other steps of obligations. We're condensing it a lot. Like I said, I'm an attorney. There's an attorney that lives inside me even though I don't practice; so I tend to want to make these events into ADA trainings. You're not going to have that today. You're going to have a quick thumbnail sketch and know that we're leaving lots of things out.

But federal, state and local governments have significant and nonwaivable obligations to children and adults with disabilities during disasters as well. And Marcie talked about how this obligation is unwaivable. So someone can't say, wait, we suspended the Rehab Act, we suspend the ADA because things are so bad. That's not how the law works. There are always obligations under the ADA. Those are never waived. Those never go away. And it's important to always remember that.

In the After Action Report we described the federal obligations and the role of these laws when providing emergency programs and services to children and adults with disabilities before, during, and after disasters. And, again, we go into it in more detail in the After Action Report and we will tell you how to access that after this presentation. So we're giving a thumbnail sketch. The After Action Report goes into more detail but is not a full-blown ADA report or full-blown report on the federal law as much as I would have liked to have made it into that.

Next slide, please, Lewis.

Here's some, some of the federal legal obligations to individuals with disabilities. Originally this was two slides and we decided you didn't want to hear about every federal law or that given our time constraints we couldn't give you every federal law; so we're highlighting the main ones.

The first is the Rehabilitation Act of 1993 as amended. You all know about that. Most of you know about Section 504, Section 508, Section 503, all of the Sections and the 504 sections, all of the components of the Rehab Act apply to individuals with disabilities before, during, and after disasters. The second one is the reason we're all here today, the Americans with Disabilities Act, the ADA of 1990 as amended in 2008. And another key law is the Individuals with Disabilities Education Act, IDEA, and that was 1975. That was amended.

IDEA is really important to understand. I'm going to talk about education in a few minutes, but understand that children, students from 3 to 21, still have a legal right to free and appropriate public education otherwise known as FAPE, under the law even during disasters. So we're going to come back to all of that.

And now I'm going to turn it over to June who will talk for a few slides about health maintenance. And then I'm going to come back.

Thank you, Lewis. If you can turn it over to June and the next slide, please.

>> June Isaacson Kailes: Ok. Hi there. Sound check. Everything ok, Lewis?

>> Lewis Kraus: Sounds great, June.

>> June Isaacson Kailes: Ok. Well, hi, y'all, from blistering hot and burning California. We are unfortunately experiencing another historic year of fire emergency.

So I just wanted to reemphasize that this report is different than many other government reports; that it's not been scrubbed, censored or sanitized by multiple often

political reviews that makes its value in terms of disability issues and civil rights compliance very high. I think it's a critical, long, and sobering review. And if you're like me and you're not a speed reader, my advice is first read the sections that resonate with you and use it as a reference, a roadmap.

You know, as a seasoned person in emergencies, I can't help but repeat and say one more time that a lot of this is not new; it's just once again blows up that overused term [Inaudible Off-mic] lessons learned. As Marcie said, this represents decades of lessons that still have not been applied as we would like to see them applied.

So I'm going to talk briefly about content from the sections I wrote from health because it began to translate the what into the how regarding access to emergency Health Services.

I'll start by saying in the emergency world, the emergency support functioning -- public health and medical services -- is one of 14 functions in the emergency world that provides the mechanism for federal assistance to state and local jurisdictions. A shortcoming is that most of the focus is at hospitals and medical facility operations.

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So Marcie talked about this already so I'm just going to emphasize that the study in the *New England Journal* done by Harvard is really a direct connect about the need to expand the focus in terms of health services for people living in the community. The study really emphasized that for the people we care about and older people, the loss of basic utility services, and many people living with chronic conditions really had a very significant impact. And the study, as we did in the report, calls for communities and healthcare to develop more inclusive and stronger plans.

The most common reported problems were the inability to get medications, the lack of power for life-saving equipment. And, again, the interruption of basic healthcare was the main cause of sustained, high mortality rate in the many months after the hurricanes.

And just to reiterate, this is not new and it's not just Puerto Rico. This has been going on for many decades, including with Hurricane Katrina and Superstorm Sandy. We saw nursing home residents and those dependent on life-sustaining equipment and power, and medications and supplies in the community, all of them being disproportionately affected.

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So, ESF8, its inadequate emphasis on people's needs really contributed to what I know many of you read and heard in the media, the story of those people dependent on critical supplies and power and medication and attendant services and oxygen and dialysis and chemotherapy and other infusion therapies and home health services. The people who were unable to access these services in these emergencies.

And some people actually -- they got evacuated from the U.S. Virgin Islands to San Juan, Puerto Rico. And then they got re-evacuated in anticipation of the hurricane hitting Puerto Rico, got evacuated because of their healthcare needs. But many of their other essential needs had significant gaps in terms of support for food, shelter, equipment, and supplies.

So with ESF8, the fix is really focusing on a broader group of people than just those in institutions. For example, the deployment of qualified temporary health professionals, including case managers, to address immediate needs is really critical. Plus, CMS, the Center for Medicaid and Medicare Services, can help lots by cutting some of the unnecessary red tape. It may sound ludicrous and I think it does but after catastrophic emergencies users have

to show copies of their original prescriptions in order to get equipment replacements when this information is actually available in the vendors' databases.

So, health plan, health insurance carriers, the VA, health centers, equipment vendors, home health agencies, and many disability organizations listening out there are often overlooked as a central resource in maintaining the healthcare and service delivery. They should be in the frontlines of protecting and maintaining the critical needs of people.

So most of what I'm going to talk about today applies to all of you even though I'm going to give examples from the healthcare world. So the speed at which health plan has to activate their response has a direct link to life and death outcomes.

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So this, again, is the what into the how. Many health plans detailed in the report really activated quickly their response. And this included responses around messaging, life safety checks, member tracking, sharing of critical health information, preventing and diverting inappropriate admissions to hospitals and nursing homes and other facilities. But these uncommon promising practices really need to be standard practices.

Health plans who were proactive had what I think is critical. They had a not if but when [Inaudible Off-mic] of the real and recurring disasters that occur where they are. They know if their members live in high hazard traffic and disaster probability areas. So these plans had some very robust training and procedures. Their call centers had protocol that included just-in-time training for all of the staff answering calls they developed and used scripts that had processes for really escalating callers for people needing immediate, critical assistance, especially when the local responders and governments, 911, 211, and 311 call centers, were overwhelmed or not functioning or not functioning well due to a huge call volume and very long wait times.

These plans maintained as their connections with their community partners in planning, in exercises, in drills, and response and recovery activities. They went beyond their regulatory requirements and the regulatory agencies and departments such as health services and healthcare coalitions. These partnerships were a critical and major recommendation in the report.

An example with Anthem, contracted with a partnership in Portlight to assist with member outreach and check-in services. And their connection was built on trust, years of a relationship in a partnership. And the pairing and the partnership offered stronger disability response, competencies, and really deeper understandings of the complexities and the nuances of living with disability and a strong and current connectedness to local and self-organized responders like the Cajun Navy.

Anthem's response with Portlight and the partnership expertise made good sense. Enlisting experienced responders in local community, engagement experts with the know-how, the creativity, the nimbleness and the flexibility to help members get immediate and critical needs met.

So other practices or promising healthcare coordinators, assisted members in developing and sustaining their emergency plans and they included in this planning for power outages, planning for extra medications, planning for an evacuation, sheltering in place, or -- and identifying support systems. And actually, the plans reviewed every 90 days so the plans posted and disseminated tailored, emergency prep messages not only to their members but members' families, attendants, and caregivers. And the prep information went beyond the general stuff because it focused also on the specific functioning needs, hearing issues, vision,

mobility, and speech, and understanding and remembering information, and the no-cost and low-cost prep.

In the no-cost prep, meaning how you identify your support systems, how you make evacuation plans real, how you collect your health information ahead of time, [Inaudible Off-mic], and how you really plan for options related to backup power for all of those essential pieces of equipment that help people sustain their health and their lives and their mobility.

So the health plan made in Texas 14,000 calls to members four to five days before the hurricane made landfall to help people activate these plans. Get those prescriptions filled early. Get their grab-and-go kits and evacuation plans ready. And the plans also, and I think this is really significant had a first contact group for life safety checks it includes members with complex healthcare needs and those who may not be able to get or understand the alerts.

Those and the infusion therapies I already mentioned, those that had power-dependent issues, and those that lacked support teams, family, friends, or people unable to get to your distribution points for food and water. So these members were pre-identified. Those were serious gaps in their plan. And they were prioritized by all of the plans in terms of who was contacted first and that worked well. Sunshine Healthcare helped members pre-emergency to board up windows. They delivered food after the emergency and medication, oxygen. And other plans mentioned in the court dispatched service workers to actually do an in-person, face-to-face check on people. Anthem with its check-ins, distributed cell phones, Chargers, and other supplies. And the plans instituted member tracking systems when evacuation resulted with people going to other counties or states.

So the plans also had protocols in terms of sharing health information. They knew what they could do under HIPAA, which often is a big barrier unless people know what to do in emergencies with healthcare, critical healthcare, information. So that was a big, important practice. And they focused also on preventing and diverting people from being admitted to nursing homes and other institutions. And when that happened, when people got caught up in the institutional net, they actually helped people transition back from these institutions to their homes or temporary housing. And they exercised flexibility in funding of non-traditional services like helping people navigate the very complex disaster and recovery aids, programs, funded air-conditioners and filters, reconstruction of ramps, accessible features, debris removal, and transportation.

And messaging occurred pre and during and after emergencies really was well thought. They thought about -- they created them ahead of time. They tested them. There were critical reminders to people about what to do before and during, you know, how to contact the plan, how to access telehealth services or doctor services online, where to go if their dialysis center or their chemotherapy center or their pharmacy was down, how benefits had been relaxed and they could seek out network care. All confident information went out in multiple modes of communication. So these practices need to be standardized across the health plans.

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So the recommended fixes, I hit on some of these already. But a few I hadn't mentioned, the states that contract with these plans need to incorporate the emergency roles and responsibilities of health plans into their contracts. Some states do. Most do not. This could really strengthen plans and actively engage plans in response and recovery.

The health plan industry needs guidance, technical support and training, and regulatory standards around these kinds of activities.

And integrating specific emergency performance clauses in the vendor contracts.

For example, vendors should really be instructing the users of life-sustaining equipment in terms of what they can do what are their options in emergencies.

We need to establish and test agreements for emergency supply delivery and evacuation services including more flexible things like use of Uber and drones and non-government capacity deliverers.

And then I already mentioned the critical thing of connecting with community partners that go beyond the regulatory health agencies.

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So that's it in a real short nutshell. I leave you with this slide which is a little more information on registries. It covers the same kind of issues of what work and what doesn't work. And that's a workshop we did that's now on YouTube that you can access by just searching for the Inconvenient Truth About Registries and it will come up.

So Melissa, over to you.

>> Melissa Marshall: Sound check. Can you hear me?

>> Lewis Kraus: Yes. You're fine, Melissa. Go ahead.

>> Melissa Marshall: Ok. I wasn't the first time. Thank you so much.

Lewis, would you go to the next slide, please?

So I'm back. One of the findings is we found, found consistently across the disasters, a failure to provide equal access to services and programs to disaster survivors with disabilities. And I'm going to break down a little of those. And understand I'm giving you not superficial examples in that they're unimportant examples but superficial examples in that they are just the tip of the iceberg. So these are some of the examples we gave.

We notice a failure to provide equally effective communication. There was lack of equally effective communication for people with communication disabilities. The example -- first I'm going to give you an example and then I'm going to give you our recommendations about it.

The problem is lack of equally effective communication in a shelter for people that are deaf. The example I'm going to give you is one man in a listening session in Texas reported that he knew that people couldn't find interpreters. He was someone who was an interpreter, someone at least who signed. I don't know the details of this so he walked around a very, very large, massive convention sent we are a sign taped to his back and taped to his chest saying "Deaf." That was how outreach was done to people that needed interpreters at the George R. Brown Center in Houston.

Other people had other issues. People who were blind had issues getting access at DRCs people had issues -- people with speech disabilities had issues being understood. This happened everywhere and across disasters, and across disabilities. So equally effective communication, which is required under the Rehab Act, and the ADA, wasn't provided. And as you know, the obligation to provide equally effective communication and comply with federal laws like the Rehab Act, like the ADA aren't suspended during disasters.

And, again, it happened to deaf people through the notification process, at shelters, and throughout the entire process. And this is true for people with all kinds of disabilities.

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Oh, let me just talk about the recommendations. Recommendations were the Department of Justice and other federal civil rights offices must enforce compliance with effective communication obligations under federal law. And the other recommendation -- and we had more recommendation that we delineate in the After Action Report so these are

condensed. But training and technical assistance must be provided to local emergency management.

So again, they still know they have to have interpreters. They know that people have to have a place where they can let it be known that they need interpreters and shelters; that the person can't be blocking the interpreter when they're on camera; that things can't be streamed across captioning. All of those kinds of things were included in the recommendations.

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Second issue, which was a major concern, is the FEMA registration process was inadequate of equal access and accommodations. So the first example is, there is in place to indicate that you have a disability and need an accommodation when you register for FEMA. So I'm going to give you one example now. These are all examples obviously are real stories.

One disaster survivor with a spinal cord injury ended up being institutionalized not because he needed to be institutionalized but he was forced to share a bed with another person, had incontinence issues and he didn't have proper bedding, didn't have proper sheets, didn't have proper incontinent supplies so he would have to get out of bed, get on to the floor, transfer to change his clothes several times a night from that he sustained significant pressure sores. So he ended up in a rehab facility not because he needed to be in a rehab facility, per se, but he didn't have the accommodation of not being able to share a bed.

When he contacted FEMA, they said he needed to share a bed. There was no place for him to indicate that he had a disability, what it was, and the kind of accommodation he needed on the FEMA form. When I called FEMA for him on his behalf at his request, FEMA said, Well, it's the rule. I said, "Do you know he has a spinal cord injury?" And they kind of said, oh, well, we didn't know that.

And that wasn't their fault that they didn't know that. There was no way for them to know. There's no place for him to indicate that. So that was one example of someone not getting equal opportunity to participate, not having equal access to the form.

The form itself was also inaccessible. Deaf people at the listening sessions, the Deaf community was in uproar saying the form simply is not accessible to people whose native language is not English. Yes, these words are written in English. It's not understandable to people that are Deaf.

I also heard that from people with intellectual disabilities, from people with learning disabilities, and from people with dementia. There are lots of people with dementia and many did not have computer access and in certain places were told that the only way that they could access the FEMA application form was through the computer. Well, if they didn't have access to a computer and they didn't have any technical skills on a computer, they weren't going to be able to register for FEMA.

So that was a huge issue again because you couldn't indicate, one that you had a disability, two, what accommodation you needed, and, three, the form was difficult for people without English proficiency to read or people with visual disabilities. I know at some of the places, some of the disaster recovery centers, people were not able to access the computers, who were blind, screen readers -- it was not screen reader accessible. And, again this individual with the spinal cord injury was in a TSA bed. So he's in the TSA bed and told he had to share because that's what it said on the FEMA form.

So some of the recommendations were -- we're making, again, condensed recommendation and you can get full recommendations on the FEMA form -- excuse me, on

the website -- is redesign and publish FEMA Disaster Assistance Application and to engage knowledgeable disability community leaders, creating the process so that it can be accessible to people that are Deaf, accessible to people with intellectual, cognitive and other disabilities.

There are ways for people that don't have computer access or don't have computer skills to access it other than being on the phone and waiting for six hours and having your phone lose its charge and lose its connectivity while you're talking. So those are some of the recommendations but just understand the FEMA form was a huge problem across disabilities, across all of the disasters.

Next slide, please, Lewis.

Education. I touched on this earlier. Students with disabilities, as I said, between 3 and 21, or birth and 21, actually, are entitled to free and appropriate public education under Individuals with Disabilities Education Act, IDEA.

So one example that I'm going to give you is a student with autism had no transportation, no school and when did he get transportation somehow to his new school, there was no transition support. So there's no one to help someone with autism who has a great deal of difficulty with transition because of his disability to transition.

Again, the other thing that happened is in Puerto Rico and the U.S. Virgin Islands in some places, in much of Puerto Rico and I want to say all of if not much of the U.S. Virgin Islands schools were closed. And because they were closed, people would go to a different school so that there would be two sessions of school. So every student would only get a half-day of education. So that meant students were deprived of physical therapy if it was in their IEP, Individualized Education Program, occupational therapy, sometimes, speech therapy, counseling services, etc., because they're only in school a half-day. They were not receiving the free and appropriate public education that's guaranteed in the Individualized Education Program. And this went on throughout the entire school year.

And, again, I'm going to keep saying this over and over again, civil rights are not suspended during disasters. So students with disabilities still have the right to receive a free and appropriate education before, during, and after disasters.

Next slide, please.

Additional equal access failures we noticed. We just gave you three. We gave you education. We gave you the FEMA form. And we gave communication. But there are also failures in notification, evacuation, sheltering that alluded to, disaster recovery centers that I alluded to, huge one was food and water distribution, also distribution of goods, home inspection, housing, and appealing and denials.

And June is saying read the report relevant to you. I'm a policy wonk so read the whole report. It's only 165 pages. I it could be good bedtime reading.

Next slide, please.

Thank you.

And now we're going to start talking about some of the things that Portlight and the partnership during the hurricanes. And this first slide I think is really interesting. I was not part of this process. I was doing other things of I was working the hotline when this happened. What these are pictures of are of a helicopter dropping medications to a person on the ground, dry ground and blue skies. What had happened was there were several individuals who had difficulty getting life-saving, life-sustaining medication in the disaster area.

You might be saying, wait, this is green grass and blue skies and it looks dry. It was dry where that individual was. She was in the Beaumont area of Texas. However, all the roads

around them were washed out so they couldn't have access to medication. So there are several individuals that had difficulty accessing medication. And through the assistance of the Cajun Navy were able to do a med drop because there were people who generously donated extra dosages of medication that they had for people with disabilities that needed them. They donated them, loaded them on with Portlight assistance, the Cajun Navy flew helicopters over and did a med dose.

So again, we worked with the Cajun Navy to pick up medication in San Antonio and transport them hundreds of miles to get them airdropped to the Beaumont area.

Next slide, please. And that was in response to Hurricane Harvey.

In response to Hurricane Irma we worked closely with the Trach Mamas. They were on our hotline, staffed our hotline. We had calls with them every day for many weeks and months. There's a Trach Mamas of Louisiana. And we developed a partnership with the Louisiana National Guard, Partnership for Inclusive Disaster Strategies, and Portlight.

One of the things we did and were part of was getting supplies, durable medical equipment supplies that the Trach Mamas of Louisiana had, getting the National Guard to pick them up and ship them to people that were impacted by Hurricane Irma. I think that was really, really exciting and a really great partnership. And if you can see, I think partnership is written on the boxes. You probably can't read that right now. So that was our response during one of our responses during Hurricane Irma.

So next, if we can go to Maria. In Maria, we did something different. We actually sent a deployment team to Maria. Typically what the partnership does, it supports local disability experts and disability advocates and people with disabilities with expertise. We support them. We send things to them. We ship things with them. We give them technical assistance over the phone. We talk to them via video. But because disability organizations were so decimated in Puerto Rico and the U.S. Virgin Islands, we actually sent a team there not to take over but because the disability organizations weren't yet opened and up and running.

So it was to support them in becoming up and running to deliver supplies and do those things. We sent whatever we could, people who were native speakers of Spanish to Puerto Rico particularly, natives of Puerto Rico, and we sent lots of people with disabilities. So it was an interesting scenario where people with disabilities were coming in not as a stereotypical victims or people impacted by disasters; people with disabilities, many of them native Puerto Ricans, came in as the people who brought the generators, the people who brought water, the people who brought the Chargers, the people who brought the equipment which is a really important statement.

And selecting people, I know the partnership had a process where they thought who would be good to do this because we're doing this kind of -- as Marcie Roth would say, building the plane as we're flying it and a plane no one has ever built or flown before. And during the process they thought who would be good to do this. And who is good at dealing with disability issues in austere circumstances? ADAPT members. So two of the front people you see in the front are ADAPT members. So that was exciting to have those members there. And to go into houses, bring the generators.

One of the reasons we weren't surprised about the much, much higher death toll in Puerto Rico is we had a team on the ground. And, again, we never put teams on the ground but because the disability organizations were so decimated and disability leadership was so decimated, supporting them, we knew there were people stepping over bodies that were kind of all over the place so we had a bird's eye view into this.

Next slide, please.

So John F. Kennedy, late great John F. Kennedy used to say that when written in Chinese the word crisis is exposed of two characters, one is the character for danger and the other character is the character for opportunity. And what he would say in that -- in situations where there's great dangers like disasters, there's also great opportunity. I think that is really important to remember. Great danger, great risk in the disasters. From that we now have opportunities and at the time we had opportunities to empower people to do things better.

We're deeply concerned, and part of the reason for writing the After Action Report is we remain concerned about equal access for people with disabilities in disasters because we didn't see it happening. What we saw is it didn't matter what someone's disability was, largely. It didn't matter what location of the country they were in. The people with disabilities were not getting equal access to programs and services across the board. Some disasters were worse than others and some areas were more impacted than others but people with disabilities, no matter where they were, weren't getting equal access to disaster-related services.

So read the parts of the report that are relevant to you and make this knowledge that we're not getting equal access to program and services and it's no one's false, per se, but we need to incorporate this still into our planning. We need to incorporate this into our policies. We need to understand that it's up to us, to help ourselves. We're all in this together. Think about ways in which we can all work better and more effective in the next disaster. And work now during blue sky times to get things changed.

And I'm exactly at 3:40, which is where I was told I was supposed to stop. And again, I want to thank the Pacific ADA Center and Lewis for making this happen. And I want to thank all of you for being on this call.

We're going to open it up for questions now. Correct?

>> Lewis Kraus: Ok. Thank you so much, Marcie, Melissa, and June. And for all of you out there, just a reminder, you can submit your questions in the chat window. We're going to get to those in a moment.

I wanted to sort of start one off with you all right now. I think Melissa just made an impassioned plea to people with disabilities. And so some of the audience here are Emergency Management Agencies and maybe nonprofits. What kind of a message does this After Action Report suggest for those people and what kinds of actions can they take?

>> June Isaacson Kailes: I can start. I think there are sections of the report that deal with community partnerships and really illustrate the significant involvement of partners at the national and state and local level from disability organizations. It was an impressive representation in terms of really -- the multiplier effect of how we can play an important role in response and recovery.

I think in the report there are recommendations related to how do we do this again. How do we kind of bake in the part of the rapid response that disability organizations need to own? And some of it is not unsimilar to what I mentioned related to health plans. There's a lot we've learned that we need to now package in our own organizations so that we can more easily and quickly unpack it next time. And there's a lot of content in the report Noor in terms of the next time.

>> Lewis Kraus: Ok. That's great. Melissa or Marcie, do you want to add anything?

>> Melissa Marshall: Yes. Can you hear me now?

>> Lewis Kraus: Yes.

>> Melissa Marshall: Ok. I messed up hitting the talk button a little coordination.

What I wanted to add is in no way is this just on the backs of people with disabilities. And I'm really, really happy that emergency responders anticipate other nonprofits are on the line. I saw some people from Red Cross and that's great because you're the best ones to convey the message. Sometimes we come in as outsiders and people might be a little bit more resistant to hear. You're the ones who can say to your organization, hey, this is real. Do you know why people died in Hurricane Maria? It's because they didn't have consistent access to Health Services. It wasn't from the storm itself. Or do you know in other places they hadn't set up interpreters or an area to meet with interpreters and this is what happens? Or understanding working with school districts and working the municipalities saying to school districts, ok, in IEPs and 504 plans, you should have emergency plans so what's going to happen to a child with autism who can't deal with transition, that should be in his IEP already, so educating the schools about that and educating everybody about those things.

Thank you, Lewis.

>> Lewis Kraus: And Marcie, did I hear you, did you want to add something?

>> Marcie Roth: I'm here because my session hasn't started but I'm just in listening mode mostly. I'm about to have another meeting.

>> Lewis Kraus: Ok.

Thanks, Melissa and June, for the answer to that. I think that sort of rolls right into our first question which is sort of answered by what you said but maybe we can get even a little more detail.

The first question from the audience: Are there any resources or groups that can or will review emergency response plans and make suggestions to improve portions of the plan concerning people with disabilities?

>> Melissa Marshall: That's certainly something the Partnership for Inclusive Disaster Strategies does and can work on. There's other people locally that can look at it. Sometimes Center for Independent Living has those skills, depending on what area of the country you're in and which centers are around but it's definitely something the partnership does.

June or Marcie?

>> June Isaacson Kailes: I would add that that is an important activity for the local community to be involved with in terms of reviewing plans. But, you know, what we found to be even more important than the plan is what's underneath, the operating procedures, the real specifics of the who, what, when, where, and how. The plans are sometimes still in that 30,000-foot level but field operation guides, the real operating procedures that get looked at. The plan tends to stay on the shelf with the checklist and the procedures tend to be the things that get used. So I think it's more important for us, the community, to review the details of what's underneath the plans together in partnership with community emergency managers and the Red Cross and other organizations that have as their prime mission emergency preparedness response and recovery.

>> Melissa Marshall: And obviously disability leaders with expertise in the local community. That's the first plan. When I say the partnership can do that, that's not a 30,000-foot level. If you wanted our assistance doing that, it needs to come from the local community. And local communities need to know when push comes to shove, they're going to have to be the ones to deal with that. So doing as much as they can and thinking things through and working with other emergency managers and saying, hey, this is -- we have a shortage of interpreters. What are we going to do? Working those kinds of details through. You know, knowing where the accessible shelters are, knowing that every place that you've chosen to be a shelter is

accessible and what that means and understanding that. So that's where the local expertise comes in.

>> Lewis Kraus: And that's great. And I would just add to the answer to that question, if you are looking for resources, also in the disability community, you can call your regional ADA Center and they will be able to find you those resources as well as the partnership as Melissa described. So those are a few way that you can help to review your emergency response plans.

Another question -- and just another reminder, people, do put your questions into the chatroom and we'll get to them.

The next question, somebody was unclear in your description -- I believe this was Melissa -- about a TSA bed. Can you describe that, please?

>> Melissa Marshall: I apologize for not explaining that. TSA stands for Transitional Sheltering Assistance. What that typically is, is a hotel. So after someone -- after the shelter is closed, people often go into TSA or transitional shelter and assistance which is in a hotel. This was a hotel room with two beds, and it was two people to a bed. So there were four people in the room.

I hope that clarifies I apologize for using the acronyms.

>> Lewis Kraus: All right. Let's see, while I'm waiting for some more questions to come in, I wanted to ask another question. I know this has been a report that you've brought in front of the federal agencies for the parts that you identified as -- that were federal issues. Can you say anything about where that is going or where in the future?

>> Melissa Marshall: I can't speak to that. Marcie, are you still on the line?

She's in listen mode so she can't speak to that either.

We're hoping that people read it and listen to it and take a recommendation seriously. Also, we are trying to have introduced Senator Casey is in the process of introducing the Getting It Right Act which contains recommendations we've made in the After Action Report. So that's something in the not too distant future that will be introduced.

And we're talking to the agencies as it is. And as Marcy mentioned earlier, we're writing a specific report for the National Council on Disability about the phenomenon of people with disabilities being institutionalized during disasters and we're writing recommendations to prevent that in the future, too, is another thing we're working on and hoping that people will hear.

June, did you want to say something?

>> June Isaacson Kailes: I would add that FEMA has just come out with its After Action Report related to the hurricanes 2017. I'm slogging through it, as a slower reader. It's interesting to compare the content between the two reports or lack of in terms of projects [Inaudible Off-mic]. A report like this continues to have a life and reference point for many point for months and years ahead. That's what happened when we produced the 2007 report on the Southern California wildfires. So it does become that roadmap for actionable change.

So I think -- it's just come out in May, so out for about two months. I think its lifespan has only begun to really have impact. I think we'll continue to see it used as an important document as we move into moving from the what to the how.

>> Melissa Marshall: I do not believe, and I could be wrong about this so don't quote me, the FEMA report did a deep dive on disability I think is fair to say.

>> June Isaacson Kailes: Agreed.

>> Lewis Kraus: Ok. Let me also add to that, that for those of you who were here last month,

did hear from the Office of Civil Rights and Civil Liberties, and Rebekka Tosado. And that office has put together their report on their listening sessions from across the country and the disasters and that is available on their website now. That has just been posted. So if you have more interest in what they were hearing in their listening sessions, you can go and listen to that as well.

Ok. Next question. Are there any updates or reports of disaster strategies to help people, families, and communities with disabilities in tribal communities? And what about plans to serve the needs of folks with disabilities who are migrant immigrants or refugees?

>> Melissa Marshall: I'm going to speak to the latter part of that question first. This is Melissa speaking. We are working on trying to get stories -- and that was something I really want to do in the second version of the After Action Report about migrants, immigrants, and refugees because, because of the climate, even though I know FEMA issued statement and Office of Civil Rights has issued statements, OCRL, Office of Civil Rights and Civil Liberties issued a statement saying they're not going to check immigration status. With things as they are right now with immigration, people are terrified to seek disaster services and I don't see that changing in the immediate future. I think that needs to be a huge priority and needs to be something that we work on. I think we need to consider that -- that's a really huge and important issue.

Remind me the beginning part of the question again. I'm sorry.

>> Lewis Kraus: In tribal communities as well.

>> Melissa Marshall: That's something that -- we always look to tribal communities when we're doing work and we're doing planning. And that's something that the Partnership always considers I know FEMA has people working in tribal communities and looking at disability issues. And I can't really speak to the full extent of that. Again, that's Marcie's area of expertise.

June, did you have anything to add about tribal communities?

>> June Isaacson Kailes: I did. The good preparation material online that's disability-specific does apply to the tribes. I think like any preparedness material, it still has to be customized to make it culturally relevant and disability relevant. I think we've got good preparedness information online regarding hearing and seeing and mobility issues. So then that has to be still used and can be used by tribes but then with the overlay of making sure that any customization happens to make it culturally relevant.

So there is good materials out there that do apply and can be used.

>> Melissa Marshall: It's critical that all the materials are culturally competent for the group they're working with and that all of the planning is disability culturally competent. So we've got the intersectionality of cultural competency. And what we've learned, as Marcie said earlier, is when people are members of multiple marginalized groups, say, people of color, say women, LGBTQ -- people from LGBTQ communities, all of those people, people who are immigrants, particularly people who are not documented, the lack of equal access is going to be compounded by every group that they're marginalized part of. And I think during planning we need to be really thorough and make sure that we're including the voices of people who have been multiply marginalized in during planning and during response.

>> Lewis Kraus: Ok. Excellent. Thank you guys very much.

We realize many of you may still have questions for our speakers and apologize if you didn't get a chance to ask your question. You can contact them at that address on the screen or you can contact your regional ADA Center at 1-800-949-4232 and we can help you

get those questions answered.

You will receive an e-mail with a link to an online session evaluation. Please complete that for today's program as we value your input.

Our next two webinars, I do want to note this for you all, will be one-year anniversary or reviews of last year's disaster. First on September 13 we will have a presentation from Maria Towne from the Houston Mayor's Office of Disability giving us a one-year review of Hurricane Harvey in Houston, and then in October we will review the situation in Puerto Rico. We hope you can join us for those. Watch your e-mail two, three weeks ahead for the announcements of the opening of the registrations for each of those webinars.

We want to thank Marcie, Melissa, and June for their time today and sharing their knowledge with us and the After Action Report. And a reminder 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).

All right. Have a great rest of your afternoon. Thank you for attending today's session. We look forward to seeing you next month.

Have a good afternoon, everyone. Bye-bye.