

REALTIME FILE

Pacific ADA

NATIONAL NETWORK LEARNING SESSION:  
RECOVERY AFTER DISASTERS AND INDIVIDUALS WITH  
DISABILITIES: WHAT WE KNOW AND WHAT WE DO NOT  
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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. The series is brought to you on behalf of the ADA National Network. The 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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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, ADA, and other relevant laws. Upcoming sessions are available at [www.adapresentations.org/schedule.php](http://www.adapresentations.org/schedule.php).

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Today's *ADA National Network Learning Session: Recovery After Disasters and Individuals with Disability - What We Know and What We Do Not*. Of the phases in the disaster cycle, the recovery phase is the longest but the least explored with respect to the experiences of people with disabilities. This session will provide an overview of what research reveals about the needs of people with disabilities and their families post-disaster. Barriers to the recovery process, as well as the resource and service roles of state and local agencies, FEMA, and voluntary organizations post-disaster will be discussed.

Today's speakers are Laura Stough, the Associate Professor of Educational Psychology and Assistant Director at the Center on Disability and Development at Texas A&M University. She directs Project Redd: Research and Education on Disaster and Disability and currently serves as the Chair of the Disability Task Force on Emergency Management for the Division of Emergency Management for the State of Texas and as Chair of the Emergency Management Special Interest Group for the Association of University Centers on Disability.

Amy Sharp is the Director of Texas Center for Disability Studies at the University of Texas at Austin. She has developed online directories and resource guides used by county

extension agents and disaster recovery case managers through the Texas. Dr. Sharp has conducted evaluation and research studies on how hurricanes impact individuals with disabilities.

Originally from California, Elizabeth Hong moved to Texas four years ago. Liz is the mother of four children, two with disabilities. She's a former Special Education teacher with a passion for educational rights, mental health, and helping to support families. She works at Texas Parent to Parent on the Family Support team providing information for families whose child has a disability.

I will now turn it over to all of you, Laura, Amy, Liz.

>> Dr. Laura Stough: Thank you, Lewis. Welcome, everyone. I am Laura Stough and I will be one of your three presenters today. As Lewis mentioned, I am Assistant Director at the Center on Disability and Development at Texas A&M University. And along with the University of Texas Center, we are two of the 67 federally funded University Centers for Excellence In Developmental Disabilities.

I know that many of you are calling from the U.S. You should know that each of the 50 states, as well as in the U.S. territories have university centers and some largely populated states such as the case here in Texas as well as in California, New York, may have more than one center.

We are a collaborating network. So, for example, around the issues of emergency preparedness, university centers such as my own and Dr. Sharp's center often collaborate on projects and outreach activities provided to people through the their state.

As you know, the topic of our presentation today is recovery after disasters and individuals with disabilities. I wanted to say a bit about why we chose this topic. Although there are a number of resources and presentations that have been done around the issue of preparedness, relatively little research has been done on recovery. And we know not too much in some aspects, about how people with disabilities recover post-disaster. Therefore, we wanted to provide this overview to you today.

We have three different objectives that we will be talking about today. First, we will give you an overview of research findings about the needs of people with disabilities post-disaster. Then Liz Hong will lead news a discussion of barriers which individuals with disabilities and their families encounter. And then Liz will be followed by Dr. Amy Sharp who will talk about recovery services and resources typically available through various organizations post-disaster in the recovery phase.

To begin, I wanted to talk about the phases of emergency management and what exactly we're referring to when we talk about the recovery phase of disaster. What you see here on the screen is an illustration of the disaster cycle. This cyclic conceptualization of disaster has been around since the 1930s. It's taken different forms. But this is the most current one.

The disaster cycle is a useful concept to refer to activities undertaken before, during, and after disaster events. And classically, the disaster cycle includes four phases: Mitigation, preparedness, response, and recovery, which you see here. There are some limitations to treating these phases too literally. These phases certainly melt into each other. And some activities take place across multiple phases.

What you'll see on the right-hand side of the diagram -- we can start here with the phase preparedness. The preparedness phase includes activities in the anticipation of efforts and actions which will lessen the impact of that hazard. The preparedness phase can include

preparing a go kit, taking shelter in a secure location, evacuating from the coastline in anticipation of a hurricane.

When we look at guidelines concerning people with disabilities this phase, preparedness, is one, again, that I think of a lot of existing guidance. And, of course, preparedness is what we want to do to lessen or even avoid the impact of disaster.

So impact occurs after the preparedness phase, so in that arrow in between preparedness and response. So we prepare and then the hazard, meaning a hurricane, tornado, ice storm, wildfire, earthquake, etc., occurs. And to the extent that our human infrastructure is overwhelmed by that hazard that creates the disaster.

When we move on to the next phase of disaster, the response phase, that is what occurs following the disaster and it includes actions taken to save lives and prevent further property damage. Activities during the response phase includes opening and managing public shelters, feeding people who are displaced, and providing emergency medical care. The emergency should be seen as still occurring during the response phase. And in some disasters the response phase can go on for several weeks.

The response phase is, perhaps, the most photographed, televised, and reported on part of the disaster cycle. Unfortunately disasters are very photogenic and the response phase receives a lot of press.

The next phase of disaster, recovery, which we are discussing today, occurs after immediate safety and survival needs have been taken care of. I'll talk more about recovery in the next several slides.

And the final phase of disaster is mitigation. Activities taking place during the mitigation phase includes those that reduce the damaging effects of a future disaster or even reduce the likelihood of occurrence of a future disaster. Mitigation can include factors such as constructing public infrastructure, for example, community shelters which can withstand future disasters, buying flood insurance which would help protect you financially, or increasing safety features of your home so that your home can withstand a hazard.

Along with the recovery phase, we have the least amount of information about mitigation and people with disabilities.

So then we come full circle back to preparedness. And together with mitigation activities that we do during the mitigation and preparedness phases have the intent to reduce the impact when a future disaster occurs.

So as you will remember from the previous diagram, recovery starts following the response phase. And during the recovery phase, agencies and organizations help affected families and communities to develop plans, to implement plans, and to implement procedures so that they can return to a pre-disaster level of functioning.

Recovery phases can last for quite a long period of time. And that depends on the level of impact of the disaster. Sometimes the recovery phase can last several years. For example, here in Texas, Hurricane Harvey occurred in 2017 and we are still very much in the recovery phase from that disaster.

Typical activities during a recovery phase include restoration of infrastructure and support systems. Resuming daily routines and creating plans for permanent housings while shelter and temporary housing may have been part of the response phase when people move out of hotels or they're in shelters, that's part of the response phase. But then in the recovery phase we see movement towards permanent housing as part of the phase. So activities during the recovery phase involve returning home, as one was displaced, or

repairing a home if it was destroyed or damaged by the hazards. The recovery includes finding ways to pay for hotels, pay for repairs, and pay for personal property that may have been lost by the disaster.

However, as the recovery phase takes longer in time, as time goes on, human material and financial resources often dwindle. And another thing that dwindles is attention from the public. Part of this decrease in attention is associated with a decrease in publicity about the disaster. For example, we're no longer hearing about Hurricane Marie why, which happened in 2017 or the California wildfires of 2018 in the news. And those communities are very much still in the recovery phase.

Unfortunately new disasters are constantly occurring. And as I mentioned, disasters are photogenic and journalists will cover the new disaster even though community may be still recovering from the disaster.

During the response phase you will often see what is called a therapeutic community. People want to donate. They want to assist. They want to put in volunteer hours to help those affected by the disaster. But as time goes on, people's attention is redirected to other priorities and other causes.

Another element we've seen in our own work is that organizations which do not usually provide disaster-related assistance, they step up to fill new roles during the response phase. But many of these organizations cannot maintain that role as time goes on. We found a number of disability-related organizations who provided important and critical resources post Hurricane Harvey. However, after about five months we saw that number decline, the number of those organizations start to decline. So offers of assistance start to disappear from websites. Funding streams dry out. And unfortunately this decrease in services and supports and attention often coincides with the start of the recovery phase of disaster. So when those emergency funds from response organizations are no longer available and then when families realize that going back to their previous home or rebuilding may not be financially or logistically feasible.

Research and evidence-based reports from past disasters reveal that people with disabilities are disproportionately affected by disasters. They are more likely to experience disaster. And when they do experience disaster, they're hit harder. So what we see in the research literature is that people with disabilities experience disaster have a higher mortality rate, particularly when the disaster includes the need to evacuate or to take quick shelter in advance of the hazard.

And if you by this this finding, this research finding for a moment, it makes sense. Right? If you have a mobility impairment and you have to run or climb or quick flee and evacuate on your own, rapid onset disasters are particularly dangerous. For example, in 2011, in the East Japan earthquake which created a Tsunami, people literally had to run for their lives.

People with disabilities are also employed at a lower rate than is the general population in the U.S. And they're more likely to live in poverty. As a result, many people with disabilities live in rental property or low-income housing which tends to be less sturdily construct order sometimes located in flood plains or other at-risk locations for this reason, people with disabilities are more likely to lose their homes and they experience proportionately higher property damage as a result of disasters.

We're also seeing that evacuation and sheltering procedures that require people to physically take evasive action often are not designed for people with disabilities in mind. For

example, multi-storied buildings may require that people who use wheelchairs wait for assistance rather than being able to evacuate with others during a disaster which can lead to increased injury and certainly mortality for people with disabilities to live or work in high-rise buildings. And for these and other reasons, people with disabilities are more likely to incur injuries in disasters.

With respect to health-related complications, pre-disaster, people with disabilities, some people with disabilities, have health-related conditions. And when they don't receive adequate attention, they may worsen and cause health-related complications for example, diabetes may be well managed by an individual. But if that individual doesn't receive insulin or dialysis during an emergency, those diabetes symptoms may worsen and subsequently cause some serious health consequences.

And then kind of counter-intuitively, although people with disabilities or other functional being a necessary needs may need additional support post disaster, past studies have shown they're often actually overlooked by emergency personnel and volunteers providing disaster response. There's a couple of reasons why this might be the case. Some personnel are not trained to identify people who may need additional support. Others may assume that a person with a disability are already being taken care of by family members or caretakers. But in addition, disability is still stigmatized in our society. And some people choose to overlook or discriminate against people who are different.

Overall, following disaster, research shows that people with disabilities often require more intensive disaster case management and have more complex recovery support needs than do others. As a result, people with disabilities along with their household members can simply take longer to recover.

So together these factors suggest that particular attention needs to be paid to the experience of people with disabilities, experiencing disaster. So some substantial collaboration and work is needed in our society to mitigate these problems that we are seeing.

Looking more closely at the experience of people with disabilities, we also find that even before the disaster occurs people with disabilities and their families experience barriers. These factors following a disaster will have ramifications during the recovery phase of disaster.

So what I'm saying here is that those factors exist even before the hazard occurs. So, as I mentioned, pre-disaster, people with disabilities are more likely to live in poverty. In part this is because people with disabilities are less likely to be employed. Only 40% of people with disabilities in the U.S. right now in their prime working years are employed. And you compare that to 79% and the rest of the adult population. So approximately half are employed.

So post disaster, in general, we see people who have fewer financial resources, encounter more challenges in their recovery. It's more difficult for them to obtain permanent housing, replace lost items, and re-establish their households. And people with disabilities often share these challenges.

Lower [Indiscernible] is more likely to be located in flood plains. And interestingly enough what is the most common natural hazard in the United States? It's flooding. Flooding. And land and rent in flood plains is simply cheaper. However, subsequently people living with already having limited financial resources are additionally at risk. So people living in flood plains are more likely to be affected by floods and thus more likely to proportion atly lose

more during these flooding events.

We also see that people with disabilities are less often -- less likely to have access to adequate healthcare. Sometimes disabilities are accompanied by chronic healthcare needs which can be complicated and expensive to manage. So think about how those needs play out against the first two points, poverty and being unemployed.

Given barriers, some of these barriers that I've mentioned but also barriers to mobility, transportation and communication, people with disabilities and their families often can end up having smaller social networks. For example, if someone is not able to travel to social events or church or to speak or to hear others, it can be more difficult to establish and maintain social relationships.

Post-disaster, what we see in research, a major source of support are friends and neighbors. So if social networks are smaller pre-disaster, then the level of support that people with disabilities can call upon post-disaster more limited -- post-disaster are more limited and less available to assist during the recovery phase.

So, barriers and societal challenges for people with disabilities even before disasters occur can contribute to more complicated and lengthy recovery post-disaster.

Contrary to the popular idea that disasters affect everyone, the fact is that disasters do not impact everyone equally. Research has found a number of demographic characteristics which lead to disproportional impact. Children, the poor, seniors, single mother, people who are unemployed, people medical needs, what happens with people with disabilities is that disability status intersects with a number of these factors. So you have a layering of these factors which compounds difficulties during recovery.

So not only are people with disabilities more likely to be impacted, the extent of the loss and the severity of that loss is disproportionate. So they remain two steps behind rather than one step. And again, the multiplicity of those barriers make recovery more complicated post-disaster.

One of the areas in which Dr. Sharp and I have conducted extensive research is on the role in disaster case managers during the recovery phase. To kind of briefly overview the role of disaster case managers, they typically work during sponsor recovery phases of disaster. For example, you may have a Red Cross disaster case manager working at a Red Cross shelter immediately post-disaster. And you may have other case managers, for example, here in Texas, BCFS is employing a large number of case managers in Texas 18 months after Hurricane Harvey hit as part of the recovery stage. Many voluntary organizations will use some form of disaster case management.

Disaster case managers connect disaster survivors to needed resources and services I've heard them referred to as resource [Indiscernible]. They connect people to resources [Indiscernible] to an individual or family and the case managers meets with the individual or family to determine current needs and collaboratively agree on recovery goals. In the case of disaster case management, they typically will be almost entirely focused on those recovery goals.

Case managers inform individuals or families about resources that might meet their needs and programs for which they meet an eligibility. You can imagine right now what an important role this is in disaster recovery since families are confronting, some of them for the first time, a time for disaster assistance. Different types, FEMA support, insurance reimbursements, etc.

And then also case managers can identify, help identify, documentation needed to

apply for assistance and guide clients through that paperwork.

So what you see in disaster case management -- and we've done research on many cases of disaster case management, particularly following Hurricane Katrina is that people with disabilities need more intensive disaster case management, specifically not only does the process take longer, it's more complex and often requires disability-related expertise. And the disaster case manager must connect people not only with disaster-related resources but with disability-related resources. And what we've heard from case managers is that due to lack of other options, they, themselves, often advocate for people with disabilities. And sometimes provide direct support such as transportation, filling out applications, or just listening. So the need for that intensive case management, it's really evident.

What these disaster case managers report is that for clients with disabilities, few are motivated and persistent. The process goes more smoothly during recovery. So when people with disabilities are advocating for themselves and active in the recovery process, that's a plus. That also illustrates to us that people with disabilities can be important agents in their own recovery process. Not simply passive recipients. So we need to make sure that we allow people with disabilities to be full partners in their own recovery paroles yes, sir.

So moving on to barriers to recovery. As I mentioned many are present even before a disaster occurs we have a society where people with disabilities are less likely to be employed, less likely to own a home, or to be able to use public transportation. But, but when we look at the recovery goals that people with disabilities have, they are really quite simply like those of any other person trying to recover from a disaster. They want to get into some form of permanent housing. They want to get their transportation system reestablished. They want to get back on their feet financially. So their goals are much as anyone else has who is affected by a disaster.

However, to do so, people with disabilities have to negotiate two different resourcing service systems. First, they have to negotiate the disabilities support system which provides things like personal assistants, special ed services, medical supports. And then they have to negotiate the disaster support system which provides temporary housing, financial assistance, food, clothing.

So what we find is simply negotiating the paperwork and requirements of these two systems can, in fact, create another barrier for people with disabilities. These systems are complex. They're complicated. And they often don't do a good job of accommodating the needs of people with disabilities who use them. For this reason training, including case managers and agencies working in long-term recovery, needs to be done on the needs of people with disabilities.

So if people understand how to remove or even decrease some of the barriers people with disabilities encounter, they can then more effectively provide recovery services and better assist people to move more successfully through the recovery phase.

I'm going to transition now to Liz Hong from Texas Parent to Parent who is going to give us some concrete illustrations and provide some family-based perspectives on the disaster recovery process.

>> Elizabeth Hong: So, when I was first looking at talking about this, I was trying to figure out how to make it a more visual idea. And I thought of this spoon theory. You may have reared of it before. It was created by Christine [Indiscernible]. She's an individual with lupus who was trying to explain to a friend what it's like living with lupus. So she grabbed a bunch of spoons and she explained how each activity in life requires mental and physical energy and for that

she uses a spoon as the quantity of how much energy you might have available.

When you or your child has a disability, it takes a lot of spoons to get through the day. At Texas Parent to Parent we talk about how when parents first have their child diagnosed, they are often stressed and overwhelmed. We call this the surviving stage. And it looks like this because they are literally using all of their spoons just to get the very most basic parts of their day taken care of.

As they start to settle in, they get more supports, either natural through their family, friends, and neighbors, their community, or they might also get formal supports which can include personal care attendants, educational services, counseling, other supports. Basically other people start putting their spoons into the pot and there are more spoons available to meet the needs of the child or the family.

And with this, the family can kind of calm down. They are less overwhelmed, they are more able to get things taken care of.

So one of the ways that we as parents, and individuals with disabilities, one of the ways that we get through all of this is by sharing the load with other people around us. That way we don't have to use every one of our spoons to get through the day and we can feel more calm and productive.

So after a disaster you might be facing more than just your own personal loss. If your family was in a fire and you lost everything, you would probably still have your support network available to help you out. But if you had a more widespread disaster, that could also affect your support network as well. So they may be experiencing loss and you might lose part of your support network. Or you might lose the whole network as well.

This could be especially true if there is displacement. And that displacement could come into place when it's you being displaced or your family being displaced, or also if your personal support network is now displaced and they're not able to fill that gap for you.

Another thing that is really challenging is the hoops that you jump through. So I have literally tried to apply for SSI for my son now four times and every time I go down there there's a problem. So I've taken a day off of work and I got to come in here. And now I have my 60 days that I got to fit it all within, fix the problem, and come back.

So for individuals with disabilities and their families, it feels like they've already jumped through all of these hoops to get all of these services and things into place. And if you have to now do it again, it's like starting a whole process over. But instead of just focusing on one, you're starting 10 new processes.

Another big loss that I think we experience is losing specialized items. And some of these are deemed medically necessary and some are not. So we have families who might need to buy special clothing for their children because they won't use jeans or shirts that are too scratchy or they need clothes that fit a certain way. They might also be purchasing special shoes that allow their child to be independent. Sometimes they'll purchase tools that help make their job go easier.

I know that recently we have someone who wanted to get a new shower chair and the insurance company deemed that not to be medically necessary because a sponge bath would do just as well. I personally would prefer a shower. And so did he. So he purchased that out of pocket. And the losses can be huge. And these things are often not deemed to be medically necessary. They make our lives easier. So the insurance isn't going to cover it. But even when you have an item that is medical necessary -- medically necessary, if you lose that, it can be a huge hit. So if you've lost your stockpile of extra diapers and now you've got

to buy diapers or your extra diabetes supply ever needles, it may take you a long time just to get back to that baseline.

Another concern is wheelchairs, a huge hit this affects individuals on every level. It's going to decrease their independence both inside of their home or wherever they're living but also out in the greater community. Oftentimes wheelchairs are used for transportation and vehicles. It has to be a specific wheelchair that meets certain requirements and without that, some individuals captain sit up in a seat in a car. So transportation becomes a huge challenge.

On top of that, wheelchairs are designed oftentimes to very specifically meet the needs of the person in the wheelchair. So they can shape it in certain ways or adjust it so that it kind of prevents any discomfort or bedsores or pain. And without that that individual may be very limited. We have a friend who is in a wheel compare and he's so uncomfortable every time he tries to use those portable ones it just doesn't fit his body. He doesn't like to stay in it. He prefers to sit on a couch and not go anywhere or use his regular chair.

So I know that for our familiar whether I if we were displaced, our number one concern would absolutely be medication for everyone. We would have to put every single one of our spoons into making sure we got the medications situation taken care of. And I think for us that would kind of put us behind everybody else because we couldn't be focusing on permanent housing or jobs or things like that as much as we would have to focus on just trying to get everything back to stable again.

So you know, losing all of your supplies and losing your network at a time when your needs increase, it really adds a lot of extra stress and challenges.

So there's a lot of needs that individuals with a disability have. And oftentimes we have to rely on other people or networks or supports to help us meet those needs.

So anytime we have that challenge, you know, we're going to have to look at how that's going to affect all of our other needs. So if you get a late start on the house game which many families did, finding a house can be very challenging. So after Harvey, the Houston market was stressed. There was widespread flooding like the city does not typically see. So there were a lot of places that were just no longer livable. So we had families who got right into the housing market search and they were unable to find housing that was accessible for their children with wheelchairs. One of them had to move out of Houston entirely which brings a whole new set of challenges, medical challenges. And another one just had to move across town. Well, this interfered with her -- her son had to start a new school, which means a whole new IEP, missing time for that, hoping we get the same services into place and everything works fine. And then it also stressed her childcare situation because now she had a longer commute to take into consideration.

And then like I was saying earlier, this also affects the medical system. So at least in the State of Texas your Medicaid is based out of what region you're in. So if you are displaced and you have to move, first thing you have to do is notify Medicaid that you have left. And I don't know if you've ever called that system but it is a disaster trying to figure out which button to push. I could never get it right. I just ask them to transfer me.

And then you're going to be look at possibly having to get a new Managed Care company for your Medicaid. So if you move out of your region, you're going to have to now switch from Blue Cross/Blue Shield to maybe united healthcare or another company like that, for example, and so the specialist that you were able to see in this area may no longer be covered in that area. So even if you were traveling a large distance is to see that specialist,

you may not be able to see them at all anymore. So now you're going to have to call your Medicaid to let them know you moved, get your insurance company picked out, call your specialist and hopefully get in or have to get a new specialist that will take you -- all of this can take a lot of spoons, and hours and hours of time.

Also out here we have our local authority. We have a local intellectual on developmental disability authority and a local mental health authority. So when you move out of that County, you have to sign up with a new local authority. So this is an even smaller service area than the Managed Care organizations.

So I live right on county line. If there was a disaster and I had to move over to the other side of the County, I would have to call up my local authority, get a new intake started before I could even receive any services, any appointments, or anything. So all of this takes a lot of time and a lot of delays.

Transportation is another huge hit. When you move out of a certain area, you may have to live in a part of the city that no longer has accessible transportation. So in Houston only parts of the city had their accessible public transportation. And I know in the City of Austin where I'm from, the parts of the city that are on that system are actually the parts that are the most crowded and the most expensive to live in. So once you move out to the outskirts or outside of the city limits, you now may not have any public transportation that you can depend on or you may have to find a whole new system that you would need to now get into that can affect your medical situation, your employment, even your social activities can be limited because you don't have that access to transportation.

So, I know specifically after Harvey one of the situations was medical transportation is provided by Medicaid but only for the individual with a disability and an attendant or a parent. So some families who were displaced and lost their support network, they no longer had childcare for their other children and were unable to make it to appointments because the medical transportation would only take a parent and the child and they didn't have that neighbor to drop the kids off.

So it hits in so many places. You're affected by how you can get around. You're affected by where you can live. You're affected in how you're going to see the doctor and whether or not you can still see that same doctor. And it also can affect your employment, especially as an individual with a disability. You're already coming into that housing market with barriers to mitigate. And so when you now have this extra hit of I don't have transportation or I just lost all of my support system that made this possible, it can be really challenging.

So our pathway through adulthood transition program, we teach parents that when your child is getting older, or you're an individual with a disability, one of the ways that you can find employment is by building a job around you. So we have families, for example, there's a family that has a cart where they make these little clusters and they take them out on their cart and they go and sell them at businesses. Well to do that, the family purchased supplies they used their own money to get the business off the ground. They also have networking so that they can take their child to these businesses and have connections with that. So if they're displaced, they've lost the supplies and they have to network all over again. And it really just can start that whole process anew. So even if being displaced doesn't hit them directly if that business is displaced or that connection and that office is no longer working there, that can be really challenging.

Another family that I spoke with, dad lost his job after Harvey and it was really hard to

get another job. So mom stepped up and got a job and was providing for the family. Well, mom's ability to earn [Inaudible] as much as dad's was. So whenever dad was able to get a temporary job, mom would have to get day off of work to watch their 15-year-old who still needed childcare. And unfortunately they didn't qualify for the Medicaid system and they didn't have a support network because mom was doing this all along beforehand.

So the family was in a constant state of juggling. Over a year after Harvey, they were still struggling to get back on their feet.

So when you look at this, it really becomes kind of like a spider web, the housing effects the transportation and the employment. And every need just plays on top of the other one as people need more help.

So when you are starting out where you have a dependence on education, disability, or medical services it becomes extra challenging when you have to prioritize needs and figure out which ones to take care of first. And then you get a late housing -- [Laughter] Late start on all of these other things, like housing, it can just add extra challenges and barriers.

Now I'm going pass it along to talk about [Indiscernible].

>> Dr. Amy Sharp: Thank you, Liz. We're going to talk about resources for long-term recovery. We're going to start out with who you are matters. After the flood of donations of material resources and man power subsidies, the long-term recovery begins. So how do survivors access those resources? Many survivors do not have insurance or do not have the correct insurance for the type of damage that impacted them and their property. At this point the survivors find the resources versus the resources finding them and many fall through the cracks for varied reasons.

Long-term recovery offers less organization and media time devoted to the availability of resources also understand that many disasters occur that impact small communities and that disaster may not bring national attention. However, the impact can be just as significant. Many of the programs and agencies offering assistance are faith-based, local and national businesses, individuals and nonprofits. However, these resources are not typically organized in tandem with each other. They historically offer what they know how to offer and this makes both finding the resources and accessing the resources more of a maze it takes a concerted effort.

This effort on behalf of the survivor can be hard to navigate. Reasons for this are many. A major issue is that most resources are accessed via an online portal of some kind. This may be the website of a business or faith-based organization but finding out who is providing what is pretty tricky. The ability to access to navigate and to search the web is pivotal. The elderly and people with disabilities may be less tech savvy or they may have less access to technology. Those in most socioeconomic status may have less tech access as well. And technology is how most of these resources are found.

Also know that more than 10% of people in the U.S. have no health coverage. So there are often basic healthcare needs that can go unmet. For at-risk populations, the long-term recovery takes even longer if it ever occurs fully. And the new normal is often adopted.

So how can your community become more prepared? The first thing is to know who does what. So we're going to talk about these three categories. FEMA is our Federal Emergency Management Agency. And they provide immediate lean long-term needs. However, the closest -- they focus primarily on housing. Our state and local governmental and non-governmental agencies provide various supports and services again, depending on

what they know how to do. Once the disaster news cycle ends, the communities are still in need. They still need access to support and resources and services.

This often encompasses the long-term recovery committees as well. The long-term recovery committees are groups -- or groups often know the communities the best, how to navigate it and the specific community resources available.

VOADs are voluntary organizations active in disasters. And VOADs are a coalition of organization that prepare for and respond to the recovery needs of America's communities in times of disaster.

Let's look a little more closely at these. FEMA's mission statement is helping people before, during, and after disasters. So this assistance may look like grants to help pay for temporary housing, repairs to the housing, looking at property losses, medical, dental and funeral expenses caused by the disaster.

Another Office of FEMA is called the Office of Disability Integration and Coordination. So this office looks to build a culture of preparedness to ready the nation for catastrophic events, and this includes and meets the needs of people with disabilities.

The Office of Disability Integration and Coordination seeks to ensure equal access and delivery of services to people with disabilities in all phases of the emergency management. They convene disability stakeholders. They develop solutions to identify gaps to meet the needs of people with disabilities before, during, and after disasters.

So each of your states has a disability integration coordinator. And just last year FEMA developed a strategic plan for 2018 to 2022. And one of the stated goals in that plan is to learn from and work with a broad inclusive base of stakeholders to understand the circumstances and challenges different groups people face, including those with access and functional needs.

So we have people out there in FEMA focused on disability and how people are disabilities can be more supported.

You can find out who your disability integration coordination representative is. And you can also be added to the e-mail list -- I'm sorry. I just got distracted. Yeah. You can be added to the e-mail list for your state. And we can share that information with you after the session.

So while FEMA works mainly with homeowner grants, the Small Business Administration is a bit more broad but focused on businesses. It's not a loan -- I mean it is a loan. It's not a grant. Loans must be repaid versus a grant that is not a debt. If insurance and funding from FEMA doesn't fully cover the disaster assistance you need, you can use disaster loans for a number of purposes. These include things like real estate, personal property, economic injury, machinery and equipment and inventory. And you can see from that list that most of these are business related losses.

So through getting hooked into the Small Business Administration, first you find out if they declared your area as a disaster. Then you apply. And then you check your status. So it's a pretty easy process. But again remember these are loans and not grants.

Long-term recovery committees are also called long-term recovery groups. So depending on your community, they'll be referred to as an LTRC or LTRG. These are people and organizations who work together to solve problems. They're very solution-oriented. The strength of the long-term recovery committees is that they are part of the local community and state communities. They have the ability to reach its members and listen to the specific needs of the community. They then work with the VOADs and local agencies to meet the

identified needs of community members. Often the long-term recovery committees find the people who have become lost amongst the overlapping systems and deliver assistance to those survivors.

One of the key elements in the community is the knowledge of the survivors' needs. They'll often present a case to the entire committee and then organizations step up where they have the capability to meet the needs of the community -- communities and the members.

For example a case I read about in Delaware was about a local flood survivor who lost her entire collection of cookbooks. It doesn't sound serious but it posed a real problem for her because the survivor is a cookbook editor. The loss threatened her livelihood. The committees's co-facilitator was able to network and with local -- which started her back on the road to recovery for both her business and her just personal worth, self-worth. A pretty cool thing.

So know that you can't just go to the phone book and look up your long-term recovery committee. You need to make contacts ahead of time. They're composed of nonprofit volunteers, civic and faith-based organizations, and other local organizations that are in your area. Many of these include Centers for Independent Living, protection advocacies, now called Disability Rights, insert your state name here. Like Texas, is Disability Rights Texas. Your universities often have University Centers of Excellence for Developmental Disabilities. The transit systems, the schools, the libraries, the Easterseals, Rotaries, Lions Club, all of those folks surely -- usually step up during disasters. Add to that your grassroots organizations on disabilities and you can probably find those just by talking with somebody who is disability savvy.

So the VOADs are the voluntary organizations active in disaster. That's what they're called. Back in 1969, Camille was a category five hurricane and hit the Gulf Coast. There was a lot of unnecessary duplication of effort. Some needs went met. Some needs went unmet. Some areas were served. Some areas were completely unserved. So the next year seven national organizations met to identify ways to coordinate their efforts. 49 years later there are over 50 organizations that comprise VOAD as we know it today. Your state and/or region will have a VOAD representative and they probably meet pretty regularly. Today regional VOAD is are a form for sharing knowledge and resources such as money, materials, and man power to prepare, respond, and recover from disasters.

And there's a link down here so you can look up your VOAD by state.

So Liz touched on and Laura touched on support systems during, after disasters. Our social relationships provide a lot of emotional support, a lot of spoons. However, these can be shifted greatly during disaster. People often get moved from wherever they were because the home was ruined. It's not livable. Or your neighbors or community members move or your organizations that you depended on for support are moved.

For example, we found in many Katrina survivors had natural front porch communities. They managed the transportation such as, hey, can I have a ride to town tomorrow? They managed their social events, hey, what are you doing on Friday night? And informal care giving, have you seen Amy lately? They did all of this from their front porches people walking by, other people walking by. When survivors were relocated, that system was greatly disrupted. Survivors may have been placed in really nice homes but it wasn't in homes where outside was a thing. I know a lot of people these days who don't even know their neighbors. So, again, a lot of people had to create a new normal. So we're back to that new normal. This

is a hard thing to do when you've lived one way your whole life or you have a lot of supports in place in your local community and you've got to go re-establish those somewhere else.

A specific tool that we use in Texas is called the REDDy Directory. It's Resources on Disasters and Disability. This directory was funded by the Association of University Centers on Disability and the Administration on Intellectual and Developmental Disabilities. And I throw that in because I have to.

So the REDDy Directory is a subset of an existing directory for Texas that houses over 2500 disability resources. When Harvey hit, Dr. [Indiscernible] had the great idea why don't we use this. We can adapt it quickly. So people could go to the DCR, the directory of community resources, in Texas, click on the REDDy Directory and you're ready to search. You can describe the resource you're seeking. You can describe -- you can type in a key word. You can put in your zip code and pick the distance, the radius that you want to search around that zip code. You can search by resource type. Or you can just go search through the existing resource that are there.

Once you click on the title of a directory, all of their information pops up, how to contact them, who they serve what they do, what their website is, what their address is, their phone number is, if there's an e-mail access. And this is a great resource for Texas during Harvey. The resource is still available because people are still recovering which is why we're talking to you today. Recovery takes a long time. This REDDy Directory is adaptable to any state. You can get in contact with us if it's something that you're interested in looking at. And we can ship it to your tech guru and they can make it work, waive their magic wand.

I think that wraps it up for us, Lewis. We're ready to open it up to the floor.

>> Lewis Kraus: All right. Thank you so much. That was an excellent presentation.

I do want to remind everyone this is a good time to submit your questions in the chat window and we'll get to that.

So, there are a couple of questions that I wanted to ask right away. First of all, one question is: What are some suggestions to make recovery services more accessible to low-income disaster survivors?

>> I would say to be prepared to know who in your community offering what. So that you are ready to go when it's time to go. You're ready to call and you know who to call.

Liz, Laura?

>> I think outreach is huge. I think people just don't know what's out there and [Inaudible] the barriers. Try to find it.

>> And when you think about accessibility, you need to think about accessibility not just through the website, right, you also need to think about print materials or you need to think about different kinds of ways of communicating with people who perhaps have visual impairments or who have reading disabilities. So you have to think about putting your information out there in different formats. It's not one form is going to fit all.

>> Lewis Kraus: Ok. And this is Lewis. Let add a couple of things here.

The question is very interesting because it's making recovery services more accessible to low-income disaster survivors. So as Liz just talked about, there's an accessible in the framework of how we understand it under the ADA and there's an accessible like can somebody, you know, use it or find it or whatever. So Liz talked about some things in terms of communications there's also if some of these services are forms or physical locations, those need to be accessible as well to people with disabilities. That's one element of your question.

The second element of your question which I think is interesting is to low-income disaster survivors. So there may be something specific. And that might be where some of Laura and Amy's answers so far about connecting in the community ahead of time plays into it because you are going to want to know for people who are low-income what are the resources for them.

Do you guys want to add anything to that as I tried to clarify that question?

>> And then, of course, the demographic of having disability status and being low-income. Those two overlap. Sometimes you have both going on.

>> Lewis Kraus: Right. Ok. Next question. How does the REDDy Directory differ from the 211 resource database?

>> Liz: I'm looking across the table and Amy just said, "It's better." [Laughter]

The difference is that in the REDDy Directory, we could really capture those pop-up responses to Hurricane Harvey. So as I mentioned, some of these organizations were performing non-traditional functions, providing water or blankets or temporary housing. And they had not performed that function before. And 211 does quite the vetting process to make sure that the services -- that agencies and organizations listed there have been in existence for at least six months. So these any pop-up kind of organizations or these organizations providing new kinds of services may not be listed necessarily under 211.

Also, the REDDy Directory was laser-focused on the needs of people with disabilities. So disability-related services and support. And 211 is a general resource directory for disaster-related needs.

In addition, our centers and our staff are very disability informed and so we knew what to look for on these websites. We knew if these organizations were offering something that, indeed, the disability community needed.

Sorry for the feedback.

Are we still connected, Lewis?

>> Lewis Kraus: Yes. You're still here.

>> Ok. Sorry for that feedback. And then also what's so difficult post-disaster is that for research -- resource guides, you're waiting for different organizations to input their information but what we did post Harvey is we went out and we looked at what was going out there in the field and searched for organizations and contacted different agencies about what they were doing in response to the disaster. So instead of waiting for organizations to input o information, we were going out there and seeking what they were and then entering them ourselves, checking those information was accurate.

So soon after Harvey we were able to populate the REDDy Directory and get it up and get it useable without waiting for those organizations to go through a vetting process.

>> Lewis Kraus: Ok. And one quick question about that. Is there somebody who people can contact about the directory? Who should they contact about the directory if they want to get more information?

>> Sure. You can either go to my e-mail which is on the screen. You can also go to our Project REDD website, [redd.tamu.edu](http://redd.tamu.edu). And you can also contact through our rediscovery program by telephone. We have a technical assistance line. And you can contact us through 979 -- ahh. I don't have the rest of the number. I'll give you my known number. 979-845-8257. And if you go to the REDD website, there is another number that will lead you directly to our rediscovery project.

>> Lewis Kraus: Ok. And for those of you who needed that contact information again, you can

find it in the closed captioning if you want to open the closed captioning. It was captured there.

One last question. It looks like this directory has many questions. How do you notify the public that the REDDY Directory is available?

>> Oh, my goodness. So many ways. So the REDDY Directory is rooted in our directory of community resources which, you know, has 2, 500-plus different organizations so we pushed it out through there. We also push it out through our two university centers on disability. So we have listservs of people that are joining -- that are part of our listserv. Our Governor's Office on Disability also disseminated that way. And also our protection and advocacy -- Disability Rights Texas, our Developmental Disability Council, 211. So we just did a whole campaign.

>> Lewis Kraus: Ok. Great. All right. New question. What actions or activities can state health departments do to assist local recovery?

>> That's such a great question. One of the elements that we talked about going on with some people with disabilities is that they have preexisting chronic conditions or medical conditions that unless they get attention post-disaster can really be complicated. And one of the conditions that is a lot of concern is diabetes. And that's certainly an area that we think that public health can be taken a look at during the recovery phase.

So, I would say thinking about what kinds of medical conditions a company -- often accompany disability -- because it's not the same thing. People who have disabilities are not sick. And they don't all have medical conditions. But looking at medical conditions that often accompany disability like diabetes, looking at seizure disorders, looking at mental health needs, those would be areas that I would suggest that public health focus on in order to support people with disabilities during the recovery phase.

>> One thing that Texas is doing I think through the Department of State Health Services is when the disaster is declared, they're asking that insurance company waives the 30-day limit on medicine and allow medications to be distributed because of the impact to the community.

>> Lewis Kraus: And I'm going to add something in here, too. I would say if you're working in a state Health Department, you may want to also connect with the state Office of Emergency Management and just coordinate services and needs there. I'm sure you already do that. And I don't mean to be saying something very obvious but that would be a good first one. And then I think what our speakers were talking about would be excellent, especially the mental health issues in the recovery phase, even during the response phase, pretty intense.

So great answer there.

Next question. What is TDEM? I'm assuming that's Texas Department of Emergency Management -- currently doing to better train its case managers and response forces to help people with disabilities in anticipation of the next disaster? Should it be doing more?

>> Lewis, can you reread the first part of that question, please?

>> Lewis Kraus: Sure what is TDEM currently doing to better train its case managers and response forces to help people with disabilities in anticipation of the next disaster?

>> So the Texas Department of Emergency Management does not use case managers but perhaps that's a misspelling. Our Health Services, Department of Health Services is overseeing our disaster case management contracts. And they are very much pushing for their disaster case managers to receive training in the needs of people with disabilities during the recovery phase. So, we've been doing a lot of that training in the Harvey-affected areas. And even though we're in the recovery phase, you always have to be thinking about

preparedness and mitigation, the next disaster that's coming down the line. So the mere fact that that -- so the mere fact that we're working towards adding knowledge and capacity of these case managers right now in the recovery phase is really an important thing.

There's different case managers used by different entities. So perhaps the person who wrote the question should know that. That Red Cross has case managers. Salvation Army has case managers. So different VOADs will have different types of training for their disaster case managers but the two major disaster case management contracts that we have right now in Texas are receiving training in this area.

I would say that moving forward, I think Texas is doing quite a lot with respect to talking about preparedness, personal preparedness, to go -- having a list of contacts, numbers. So talking about what individuals should be doing to prepare. But preparing social service providers, providing -- preparing case managers, those are all really good things. That function doesn't necessarily, though, fall underneath TDEM. It does under a number of different VOADs. I would like to see a lot of training of case managers and professional personnel moving forward in addition and to the focus on personal preparedness.

>> Lewis Kraus: Ok. And let me also just sort of mention to anybody out there who is in this situation and looking for that kind of training, do keep in mind the network of ADA centers, that is what we do. We do training on issues around understanding the needs of people with disabilities and their rights and organizations' responsibilities under the ADA in emergencies. In fact, the ADA still holds. So don't forget us. And you can contact the centers at 1-800-949-4232.

And then we have another question for you here about a volunteer -- sort of a neighborhood emergency team, a -- is there anyone leaders can meet with to discuss supplies that they should have on hand, insulin, chilling pouches, defibrillators, etc.?

>> That is a phenomenal idea. I lot of idea of neighborhood groups and CERTs starting to think about the needs of people with disabilities as part of what they do. So whoever wrote that, kudos that you're thinking along those lines.

As Lewis mentioned, there's a number of these webinars archived. And I think there is more work done on preparedness with respect to what people with disabilities need during the preparedness phase and evacuation phase. FEMA has to go kits lists on their website. And we're happy to talk to you as well. As Centers on Disability, we provide services and outreach throughout the state. That's part of our mission. You're welcome to give even of us a call.

>> Also, you might contact your VOADs to see what -- historically they found the needs were that went unmet and that might be a way to fulfill that need.

>> Lewis Kraus: Let me, if I can, add again. I think that you -- the questioner has a really interesting point as well. And I think if you think of this as we've tried to drive home in this webinar series that all emergencies are local and then they get escalated up to larger and larger entities, if you're a local group, your first line that you might want to talk to are is your local emergency management office and see if they have and if they're planning for these systems or these devices or supplies and how that works. And then that will help you figure out what it is that might be needed that they aren't able to do if you are capable of doing it. And then coordinate how it's able to be accessed in an emergency.

So this, again, goes back to that circle that they showed us here at the beginning. This is really that whole big preparedness phase where the preparedness is not only an individual point of view. It's the preparedness on the organizational and the systems point of view. So to

the extent that you can plug into that system and make sure that we're not duplicating effort and what not, that will really help everyone individually.

Anything else you guys want to add to that?

>> Yes. And I would encourage reaching out to your local center on independent living. The majority of people with disabilities live in the community and these centers on independent living support people with disabilities living in their communities. They're a terrific network. They're terrific resources.

When we talk about what would be kind of who we would love to get at the local level talking to each other, it's the emergency manager, it's somebody from a Center for Independent Living, and somebody from a long-term recovery group. We would love to see those connections being made.

>> Lewis Kraus: Excellent point. True. True.

All right. We realize that many of you may still have questions for our speakers and apologize if you did not get a chance to ask your questions. You have their contact information there on the screen. Feel free to contact them by e-mail and ask your questions there.

You can also contact your regional ADA Center at 1-800-949-4232 if you have any questions related to the ADA about this issue.

You all will be receiving 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.

We want to thank our speakers today, Laura, Amy, and Liz for sharing their time and knowledge with us. It was an excellent presentation. Thank you all very much.

And a reminder that today's session was recorded. It will be available for viewing next week at [www.adapresentations.org/archives.php](http://www.adapresentations.org/archives.php). And our next webinar on April 11 will continue our focus on recent emergency preparedness and management research as Robin Gershon discusses the results of a recent survey of emergency managers in Region IX, federal Region IX. We hope you can join us. So watch your e-mail two to three weeks ahead of time for the announcement of the opening of that -- of the registration for that webinar.

Again, thank you, Laura, Amy, Liz. And to all the rest of you, thanks for attending today's session. Have a very good rest of your day.

>> Thank you, Lewis.