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Introducing the Capacity-Building Toolkit for Including Aging and Disability  
Networks in Emergency Planning  
June 7, 2019

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>> I'm here, Wanda.  
>> All right. Wonderful. All right. Regina, are you still there?  
>> Yes, ma'am!  
>> Okay. Great. So, we can begin. Cheryl, do you want me to open the call like you did before? Or Regina, do you want to take it?  
>> I would like you to do it again, if you don't mind.  
>> Sure. I will open it and say thank you for attending and I will turn it over to Regina.  
>> Yes. That's correct.  
>> Okay.  
>> Wanda? Are you advancing the slides again?  
>> WANDA: Yes, I will. Does that work for you?  
>> Either way. Whatever you prefer.  
>> Do you have it up on your end?  
>> I see it. But I don't know if I have control to advance.  
>> It will be easier for me just to do it.  
>> Okay.  
  
>> Okay.  
>> Just remember to say next slide for me.  
>> Yep.  
>> All right.  
>> Wanda?  
>> Yes.

- >> I would like to know, am I also supposed to do the closing as well?
- >> Yes, you are.
- >> Okay. Good. All set.
- >> Okay. All right! I'm going to give a brief pause and then we will begin.

Hello and thank you for attending today's webinar. Today's webinar is being sponsored by AOD and the webinar is on the new tool kit from HHS/ASPR: Capacity-building toolkit for including the aging and disability networks in emergency planning.

At this time, I will turn the mic over to Regina, who will introduce our speaker for today, Cheryl Levine.

>> REGINA: Hello and welcome everyone. I would like to thank you for taking the time to join us in a second webinar in the series, a triannual event for the administration on disabilities to provide information on disaster-related activities. My name is Regina Blythe, project officer for ILA. This is within the administration on disabilities known as ALD, all part of the U.S. department of health and human services, known as HHS.

In this webinar, our featured speaker is Cheryl Levine with the office of the assistant secretary for preparedness and response, also part of the U.S. department of health and human services. Cheryl will describe the new capacity-building tool kit and talk about the aging and disability task force. I had the honor of getting to know and work with Cheryl when I served on this task force as a subject matter expert. So, as a special assignment that I get to provide opening remarks for this webinar. Without further ado, I will turn the presentation over to Cheryl.

>> CHERYL LEVINE: Thank you so much and thank you so much for joining the webinar. I'm the senior advisor for at risk individuals within ASPR at HHS. And I am here to present the new capacity-building tool kit. Next slide, please.

Next page, Wanda. Okay. First, I will give you a little background. I developed this capacity in collaboration with the administration for community living to be a resource for the ageing and disability networks. So begin, it's important to frame the role of HHS agency's involvement with the project. And next page.

HHS is divided into two types of organizations. We have what we call the staff divisions or STAFFDIVs, which are located within the office of the secretary, which is where ASPR is located. The other types of organizations are what we call operating divisions or OPDIVs, which includes ACL. A STAFFDIV has the ability to work across agencies to leverage our many partners for emergency preparedness, response, and recovery activities. There are many OPDIVs across HHS such as ACL, each with its own missions and program grantees. Next page.

Next, I will briefly describe the role of ASPR. Our mission is to save lives and protect Americans from 21st century health security threats. We work to strengthen our nation's public health and medical infrastructure and improve as necessary to quickly coordinate a response to national emergencies. Preparedness for, response to, and recovery from disasters and public health emergencies. We collaborate with hospitals, health care coalitions, biotech firms, community members, local, tribal and community leaders, and across the country to improve readiness and response capabilities.

A little bit about ASPR's history. In 2006, ASPR was established in the wake of hurricane Katrina to prepare for and respond to adverse health effects in the event of a public health emergency or disaster. The public health service act forms the foundation of HHS's legal authority. The act was amended in 2006 and 2013, and we're currently awaiting the final step of our third reauthorization, which will be called the

pandemic and all hazards preparedness and advancing innovation act this gives us the authority to coordinate public health and medical response as well as to work to address the functional needs of at-risk individuals.

So a little more about our legislative requirements. Section 2802 requires taking into account the access and functional needs of at-risk individuals, including public health and medical needs in the event of a public health emergency. This includes children, pregnant women, older adults, people with disabilities, and others. Section 2814 of the PHSA establishes eight requirements. For example, one of these activities is disseminating and updating best practices, which the capacity-building tool kit helps to fulfill.

So it's important to pause here and explain language and terms. In the original legislation, the pandemic and all hazards preparedness act, the term was used to assess the special needs of individuals. However, we know that language is important and terms do change. In the past, we have used terms such as special needs, vulnerable populations, hard-to-reach populations, and at-risk individuals. To be consistent with our partners at DHS and FEMA, we now use the term "access and functional needs." Federal agencies worked to develop an official definition that was codified in the DHS lexicon in 2017. And this is the language and approach that's used throughout the capacity-building toolkit.

Okay. So, what exactly are access and functional needs? Access and functional needs refers to people who require assistance due to any condition which can be temporary or permanent that limits their ability to take action in the event of an emergency. Access-based needs are ensuring that resources are accessible to all individuals, including social services, accommodations, information, transportation, medications to maintain health, and so on. Function-based needs are restrictions or limitations an individual may have that require assistance before, during or after a public health emergency or disaster. Access and functional needs can overlap.

Okay. So, next I'll provide a little background on what led to the development of the capacity-building toolkit.

Here we are, Regina. Back in 2017, we had a series of devastating hurricanes, Harvey, Irma, and Maria caused devastating damage. ASPR partnered with two agencies, the administration for community living and the office on civil rights to create the task force to address social services needs. Members of the task force included Kathleen, Regina and also the office of civil rights. These three HHS employees worked full-time to leverage HHS regional staff and grantees to gather information. You may recall in Puerto Rico and the U.S. virgin islands, the cell phone network was destroyed. Obtaining situational analysis was critically important to highlighting impacts to older adults and people with disabilities. And as a first step, the task force facilitated effective communication and information sharing with HHS regional staff and the local networks. They also assessed impacts to programs that provide essential support services to older adults and people with disabilities. These focused on the status of building structures and availability of accessible transportation as well as water, food, electricity and personal.

With this information at hand, the aging and disability task force was able to accomplish several tasks. First, they provided technical assistance to further incorporate civil rights law into emergency response and recovery activities for older adults and people with disabilities.

Second, recommending response and recovery activities for programs impacted by the hurricanes. And third, developing strategies for accessing functional needs for people who were evacuated due to medical needs. This was the first time

ASPR convened a short-term task force as well as the first activity requiring to work across both aging and disability programs to assess access and functional needs simultaneously. During a disaster response, having an on-site aging and disability task force helps to highlight needs to address access and functional needs. The task force focused on addressing needs of older adults and people with disabilities who live in the community, in order to maintain health during a federal emergency response and serves as a model for coordination within HHS. I truly believe it was a best practice, and if needed, we could partner with HHS agencies to enhance our response capabilities in the future.

So the example of containing the ageing and disability task force, we were able to highlight the important role of ACL's programs for addressing access and functional needs. It was an important chance to demonstrate that ACL grandee programs that work every day to support the access and functional needs of older adults and people with disabilities also plays an important role in supporting consumers in disasters and public health emergencies.

So working with ACL, we were able to assess the types of activities undertaken by the ageing and disability networks in the event of an emergency. Activities such as conducting wellness check, identifying gaps, providing situational awareness, providing case management, referral, and legal expertise, as well as addressing the need for housing and transportation services and working to facilitate access to facilities for those in need.

In the effort, we established descriptions of the types of activities that aging and -- working to increase the awareness of public health officials about these important partners. Specifically, ACL provides grant funding to community-based organizations for programs to support older adults and people with disabilities so they can remain in their homes and communities. The knowledge, experience, and expertise of the ageing and disability networks are critical to disaster and emergency response. They can assist with identifying access and functional needs and provide outreach to older adults, people with disabilities, care givers and family members. These community-based organizations can play a vital role as subject matter experts to ensure that consumers have access to community services, supports, and disaster assistance. Disruption of services due to emergencies create a risk for older adults and people with disabilities may not continue to receive services, which could have life-threatening consequences.

So next, I'll describe how we built the capacity-building toolkit, what the next step in my ongoing collaboration with ACL, I wanted to gather resources and explain planning. The capacity-building toolkit was developed by ASPR with guidance from colleagues at ACL, build through a cooperative agreement with NACCHO and the association of state and territorial health officials or ASTHO.

A key part involved holding stakeholder engagements. We hosted two in-person meetings in March and July of 2018 to describe what the capacity tool kit would be and solicit feedback from stakeholders. We invited many organizations as referred by ACL and wide representation from national stakeholder organizations. We conducted a focus group in 2018 where we invited members of the aging and disability networks as referred by ACL. This gave us an opportunity to review and discuss a draft version of the capacity-building toolkit with the folks who were the intended users. Additionally, we held phone calls with the focus group folks who were unable to attend. And finally, there were multiple rounds of review, comment, and feedback to complete the development of the capacity-building toolkit.

Ultimately, the capacity-building tool kit provided three overarching goals and

requirements. The first is to provide equal access to our nation's emergency preparedness, response, and recovery resources. There are three primary goals, the first is to provide information to become more engaged in emergency planning. We want to support these community-based organizations in their own organizational readiness plans. Second, we want to advance whole community planning. We provide tools and information to community-based organizations in order to support consumers in building their own personal preparedness plan. And third, we want to guide the community-based organizations to work directly with partners in their local communities.

Next, I'll take a deeper dive into the three main goals of the capacity-building tool kit. The first goal is emergency planning for community-based organizations. The capacity-building toolkit provides guidance for helping the ageing and disability communities undertake their own planning such as conducting risk assessment and creating an emergency operations plan are covered in detail. An emergency operations plan is an ongoing plan for responding to a wide variety of potential hazards. It describes how people and property will be protected. It details who is responsible for carrying out actions and details people and supplies available and how they will all be coordinated. So, we took the opportunity to explain in a simple way how to develop an emergency operations plan.

Another important component is understanding the incident command system. For emergency managers, this is the nuts and bolts of what we do every day. ICS is a standardized approach to command, control, and coordinate emergency response. It provides a common hierarchy within which responders from multiple agencies can work together. The same approach is used at the federal, state, and local level. So, we want to make sure that the aging and disability networks understand how it operates.

Another important area is understanding the basics of emergency support function. The emergency support functions, or ESF, are governmental capabilities organized into groups to provide support, resources, and services to save lives, protect property and the environment, restore essential services and critical infrastructure, and help disaster victims in communities return to normal. For example, HHS leads the emergency support function 8 that includes public health and medical services. So, we wanted to describe what these ESFs do and how they're organized. Other topics include participating in trainings and exercises, engaging in consumer advocacy and ensuring that older adults and people with disabilities are included in emergency planning processes.

The second goal is advancing whole community planning and supporting consumer preparedness. The toolkit accomplishes this by providing ageing and disability networks with resources to support consumers in their own personal preparedness planning. This includes things such as discussing emergency plans and the supports needed in the event of an emergency. We provide information to help consumers to understand the emergency services that are likely to be provided in the event of an emergency. Additionally, we provide information on supporting consumers with preparing their own emergency kits, understanding safety checks, and helping to navigate disaster assistance if a person becomes a disaster victim.

The third goal is developing partnerships. Specifically, helping ageing and disability networks develop partnerships with emergency managers and public health officials. Here, the capacity-building tool kit provides guidance on activities such as sharing situational awareness, which is the ability to identify, process, and comprehend what emergency managers call the critical elements of information about what's

happening in a situation. As I mentioned earlier, one of the promising practices from the 2017 ageing and disability task force was gathering situational awareness by reaching out to staff and grantees at the local level to identify gaps in services, assess needs, and recommend solutions. Another important role for community-based organizations is that of subject matter expert on addressing access and functional needs. We want to increase awareness among emergency managers that ageing and disability networks are available for sheltering, evacuations, transportation, and access to support and services. An important part of the capacity-building toolkit is highlighting these CBO as planning partners. They have data, information, and trusted relationships with consumers and care givers, which are an important feature in emergency planning.

There's been a lot of progress in using reliable data to inform our emergency planning. And likewise, building relationships among communities, organizations, and responders in advance of an emergency is important. I recommend that emergency managers and public health officials leverage relationships with partners like the aging and disability networks in lieu of building ad hoc registers using ad hoc data with the special needs registry.

At HHS, we recognize that some states and locations do use registries. However, I'm going to point out there are several considerations to using these special needs registries. First is cost. There is a cost involved with developing a registry. There's significant cost involved with collecting, protecting, and organizing personally identifying information for developing a registry. Maintenance, or keeping the data up-to-date requires sophisticated resources and technical skills. It must be managed and maintained to ensure that it's useful. And utility. Many communities and counties provide these opt in registries. The data must be kept up to date. Often they run the risk of becoming incomplete or out of date.

Resources. There's a risk of sending emergency responders to registry locations that are out of date, which could use up valuable time and resources. Redent assumptions. Those who opt in may falsely assume that someone may come to get them and therefore they may not take responsibility for their own personal preparedness. Ineffective. Some communities do not have the capability to effectively use the registry data or the capacity to produce local situational awareness of their access and functional needs population. And for all those reasons, HHS does not recommend using registries, but recommends partnering with the ageing and disability networks so they can rely on the data they have on consumers.

So a little more on data and tools. Other data recommended is the HHS empower program. This program uses multiclaims data from Medicare to identify and provide maps of individuals who live independently and rely on electricity-dependent medical equipment and services. Others include using national data to provide information on older adults and people with disabilities in your local community.

Effective communication is another important theme throughout the capacity-building toolkit. Community-based organizations can partner with local responders to ensure effective communication. One example is creating what we call a COIN, a communication outreach information network, where emergency managers may work with individuals to serve as communication outreach resources. For example, ageing and disability networks may help to distribute emergency messages to consumers and caregivers. Also, by providing effective communication with consumers, community-based organizations can work with consumers to discuss emergency planning, identify the supports that are needed in the event of an emergency, and discuss the types of services that will likely be provided in the event of a disaster or public health emergency.

Throughout the capacity-building toolkit, we highlight examples of best practices that already exist. We borrowed from other resources and synthesized existing information to provide a product where you can find checklists, resources, tools, and guidance. One sample is a list of information to help think about effective communication for people with disabilities in emergencies. This includes hearing the warnings. People must be able to receive and understand messaging before they're able to respond. Understanding the warning. Different people may have different understandings of what the warnings mean. If it's insufficient or inaccurate, they may opt not to follow these emergency instructions. Developing belief in the risk. Trust can depend on who issues the message and how it is delivered. People must have trust in the disseminator of the alert or warning. Or as I mentioned before, through a COIN, the aging and disability networks can be effective disseminators of emergency messages to consumers and caregivers.

Personalizing the risk. People must believe the alert was meant for them before they will respond. And deciding on a course of action. Personal factors influence individual responses. Using everyday approaches the consumers are already familiar with are more likely to be effective in an emergency.

The capacity-building toolkit provides information on many aspects of emergency planning. One module describes evacuation and transportation. We thought it was important to explain the role of transportation in emergencies. Under the emergency support functions that I mentioned earlier, number one is transportation. In an emergency event, emergency managers are able to take command of all transportation resources in the community. So, it's important for community-based organizations to review their memorandum for understanding and contracts with the partners. And to include the partners and describe the relationships in training and exercises. Helping emergency managers to understand that older adults and people with disabilities rely on transportation services to maintain health and may have medical needs to access transportation in the event of an emergency. These four elements of evacuation serve as a simple checklist to think of evacuation and working with consumers, starting with notification. What is the emergency? Next, way finding. Where is the way out? Then addressing independence and accessibility. Can I get myself out, or do I need help? And finally, if assistance is needed, what type do I need? Next page.

Another example of a best practice comes from a tool developed during hurricane Katrina, the SWIFT tool. Communities and organizations can use this tool in helping consumers prepare for emergency sheltering to ensure compliance with the ADA and to address functional limitations in shelters. This resource focuses on addressing activities of daily living and the types of accommodations individuals may need in an emergency shelter.

Community-based organizations should be aware of federal laws, executive orders, and national guidance that address requirements to protect the rights of older adults and people with disabilities. Among these federal guidelines are specific to public health emergencies while others offer protection against discriminatory policies, practices, and procedures and are not waived in the event of an emergency situation. The capacity-building toolkit provides plain language description of legal requirements that provide rights to older adults and people with disabilities. These federal requirements are applicable to all state and local governments as well as public and private entities. These federal laws, executive orders and national guidance provide and enforce equitable access to programs. Awareness of understanding of these federal requirements as well as any applicable state and local law will help aging and disability networks to collaborate with emergency planning partners and educate

consumers on self-advocacy. One example is the privacy law of 1974, which covers all personally identifiable information held by federal agencies. It establishes a code of fair information practices that governs the collection, maintenance, use, and dissemination of information about individuals by federal agencies. Personal information maintained under a system of record may only be shared in accordance of the privacy act, its implementing regulations, and a systems of records notice. Privacy act generally prohibits disclosure of information without the advanced written consent of the individual, subject to specific exceptions.

A systems of record notice includes a section on routine uses such as when a federal agency may share information and with whom they may share information without advanced consent. These can vary, so sharing personally identifiable identification collected during a disaster may vary by different agencies.

Another topic covered is legal support and advocacy. We know that many ACL grantees provide legal support to consumers. For example, the national center for law and elder rights, the ADA national network, and the senior legal hotlines are just some examples. Grantees of federal funds may have a role in promoting the rights of older adults and people with disabilities. We wanted to highlight the importance of this role that the ageing and disability networks play in legal advocacy and support and remind them of the importance of working with emergency managers, public health officials, as well as supporting the legal and self-advocacy of consumers.

Next, I'll mention the role of community-based organizations and recovery. Following a disaster, after the response, the longest phase is typically recovery. Community-based organizations may want to conduct an assessment of operational and financial impacts to their own organizations, assess impact to their staff members, and find out if they're eligible for financial assistance. They may want to develop lessons learned to help in planning for next time. In their role, partners working with officials, ageing and disability networks may want to include lessons learned. They may want to be included in a hot wash or after action report. This is a document summarizing key information related to the evaluation of an exercise or an incident. It should include an overview, while highlighting the strengths and areas for improvement. Findings developed from an after-action report may contribute to an improvement plan and updating emergency plans to reflect lessons learned.

Recovery also includes supporting consumers, and we know the ageing and disability networks play a critical role here. For example, returning home, seeking disaster assistance or identifying temporary housing are important and sometimes challenging activities following an emergency. One of the resources we highlighted in the capacity-building tool kit was developed by my program. This fact sheet on working with older adults and people with disabilities, tips for treatment and discharge planning helps planning for consumers living independently in the community to find the resources to resume living in the most integrated setting following a disaster. Other things include applying for FEMA individual assistance as well as providing case management and providing referral services.

Okay. So, overall, the capacity-building toolkit explains emergency planning in basic terms, includes CBOs that may be new to the role as well as advanced resources to those who may be more engaged. While we don't expect you to wear another hat as an emergency manager, we do provide information to make sure you are informed and able to work through your own organization to work through disasters and public health emergencies. We help you to build capabilities for supporting consumers during emergencies and processes for supporting consumers in developing their own personal preparedness plan. The toolkit introduces emergency managers and public



health officials to the knowledge and skills of ageing and disability networks and encourages building those partnerships. We provide resources on important activities, best practices, and provide the links to access recommended resources and tools. And in addition, at the end of each module, we provide a brief description to other resources we thought would be relevant. And finally we provide resources you can use, including templates, work sheets, checklists, definitions of terms and other information you can put to use in developing your community-based information plan and for working with consumers to support their own emergency planning.

Okay. Thank you for participating in the webinar. And I hope you will make use of the capacity-building toolkit for including aging and disability networks in emergency planning. You can find it at [www.phe.gov/abc](http://www.phe.gov/abc).

In addition, you can also visit ASPR's web page, and we have lots of resources and information available, including many of the resources I mentioned earlier and plenty more. I would like to thank a moment to thank ACL for ongoing support and collaboration. Again, thank you to Regina and to everyone at ACL. The work we were able to undertake in standing up the aging and disability task force in 2017 represent the best practice and provided a really important opportunity for us to highlight the critical role that ACL programs play in supporting older adults and people with disabilities in the event of an emergency. Thank you, ACL.

Back to you, Regina.

>> REGINA: Thank you again for your leadership and this valuable information and contributions to the presentation. I also would like to thank Allison, the director of AIDD, and Daniel Davis, policy analyst at ACL, for planning an organization of this webinar. But most importantly, I would like to thank everyone again for listening to this webinar. I hope everyone will use this toolkit and take the information and make it useful for your day-to-day planning activities. We look forward to bringing you another webinar late summer of 2019, and look forward to your participation and engagement as well.

Good-bye.