

Assisting Puerto Rico and the Virgin Islands: What the network can do to help

Thursday, March 22nd. Breakout Sessions.

Kimberly Mills:

- Currently, there are no Wi-Fi or ethernet cables. Recovery has not been linear, and of their two campuses, St. Thomas campus is in better conditions. Basic infrastructure is missing, and staff have been using cell phones to conduct business, rather than established landlines. Both hospitals have been significantly damaged as well.
- Telehealth is an area which merits further exploration, as they will never have the full number of experts needed in-person (particularly when it comes to disaster risk and resilience)
- The UCEDD has been approached to assist with the residential program (behavioral health related), but there is the concern that the UCEDD staff are taking on numerous responsibilities
- Weren't incorporated with FEMA prior to conversations with Dawn and Andy
 - A greater network is being formed, but need to be in the flow chart for designated responsibilities. Structural level changes are needed.
- Have used the funds provided for emergency AT needs (hearing aids, etc.), but this is still ongoing
- People with disabilities need a script for how to communicate with organizations (like FEMA, insurance, etc.) regarding claims
- What would be helpful would be a visual representation of what people need to do
 - Example of this would be a video to help people understand, since lengthy wordy brochures can be confusing at times. These videos can highlight what needs to be said by people in claims, as well as informing people of their rights in these situations
 - Radio is best for older populations, along with newspaper print

Tafaimamao Tupuola:

- Curious to see how many states and territories have access to their state's emergency plan?
 - UCEDDs are not incorporated into these emergency support plans. This poses a risk because once a disaster strikes, the UCEDD must know how to respond and which emergency support function to prioritize
 - These concerns lead to overwhelming responsibilities for the UCEDDs on both the community and management level
- There is an equity issue: Assistive devices and durable medical devices should be separate from household claim, mainly because this claim does rebuilding, not replacement
 - This issue would be more of a congressional issue, just a concern raised
- People need to be informed of the tricky situation regarding navigating claims, such as the difference between contributions and donations when it comes to claiming durable medical equipment in claims
- Regarding the visual aid: Why not include both the brochures and the video?
 - Yes, the brochure can get too intense, but multiple formats are critical to information dissemination. A video can be quicker to produce and disseminate too
- Need to utilize Disaster Legal Services to assist with claim rejections

- Websites and forms must be fully accessible. For example, to an individual with IDD, the term “dwelling” may not be the most user-friendly.
- On the federal level, there seemed to be a lack of collaboration and coordination. On the state level, need to get involvement into state plan, and delegate which organizations are responsible for specific emergency support functions

Anthony Cahill:

- Regarding the visual aid: People with DD react better to heavily adaptive communications. Visual cues are helpful in the interpretation of information. The major issue is that there often may not be access to technology in this population
- Social media may not be best for all purposes. In fact, the media must be adapted or the specific purpose on hand
- Need to take the lessons learned and translate them into mitigation and preparation
 - This will involve systematic work: how can we learn from what happened and how can things be prevented
 - The interest for these issues has dried up, and so has the funding
 - Must take inventory of resources prior to the disaster. This will be helpful in the accurate filling of claims post-disaster
- FEMA already has “Integrating Functional Needs” course, but it isn’t being used to its fullest potential
- We have an Emergency Preparedness SIG. This might serve as the catalyst to formally collect these issues and ensure that it doesn’t happen again. The focus must be on recovery and preparedness.

Carol Salas Pagan:

- Regarding a visual aid: They didn’t even have electricity, how can one see these videos or fill out forms for claims if one can’t access the websites or use mobile telephones
- We need to rethink how we reach populations and develop contingency plans
 - For example, the deaf community was hit particularly hard because all critical information was being sent on the one radio station still in service after the hurricane
- With a large percentage of people getting their claim denied by FEMA, we need proper navigation of the applications and the process around it
 - There is often confusion regarding why people are getting their claims denied. The Independent Living Center frequently has meeting to try to gain a better understanding of this
- We need to rethink emergency preparedness for people with disabilities
 - Not just with AUCD, but a real MOU with FEMA and HHS
 - Still dealing with the legal issue of sharing information with FEMA
- Collaborative agreement between DD Network, ILC, UCEDD, PNA, and AT Program
 - Divided the island into municipalities to obtain information
 - This was important because at the moment, they are 70 days from the start of the next hurricane season
 - Currently trying to get meetings on the Hill and meetings with people from FEMA and HHS
 - They are currently looking for people to assist in the creation of a realistic emergency recover plan
- A system of experts is needed. Also, resources that were promised to them sometimes never got to them

- Anyone who wants to assist with reading MOU is welcome
 - FEMA didn't honor the MOU with AUCD concerning information sharing