

Inclusive Emergency Management Preparedness, Response, and Recovery

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Summary

In the spring of 2018, the Association of University Centers on Disabilities (AUCD) conducted telephone interviews with University Centers for Excellence in Developmental Disabilities (UCEDD) in the US Territories of Guam, Puerto Rico, American Samoa, and the U.S. Virgin Islands regarding emergency preparedness in the Territories, the impact disasters have on children and adults with disabilities, the individuals who serve these populations, and the role each center plays during and after a disaster. This white paper provides summarizes key learnings from recent disasters impacting specific Territories and policy recommendations for UCEDDs, as well as government leaders at the Federal, State, and Territorial levels.

Background on AUCD

AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. Currently, there are 67 UCEDDs, at least one in every US State and Territory. UCEDDs are placed in a unique position to facilitate the flow of disability-related information between communities and universities. UCEDDs act as a bridge between universities and the disability community. UCEDDs work with people with disabilities, members of their families, Federal, State, and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to support all their citizens. As engaged members of an active network, UCEDDs can easily share innovations and effective models of practice in States and communities throughout the country leveraging investments and affecting many more lives than any individual UCEDD could alone.

Interview Methods

AUCD staff reached out to UCEDDs from American Samoa, Guam, Commonwealth of the Northern Marianas Islands (CNMI), Puerto Rico, and the US Virgin Islands via email requesting their centers participate in the interviews. Interviews (n=4) were conducted and were approximately 60 minutes long and were recorded for analysis purposes. Due to scheduling conflicts and transitions in leadership, AUCD was unable to interview with the CNMI UCEDD. Once interviews were completed, two AUCD staff performed a themes analysis and developed recommendations based on these themes.

Aftermath of Disasters in the Territories

Almost each Territory had a major disaster occur within the last year. Earlier in 2018, American Samoa had cyclone Gita which was a tropical cyclone that caused two fatalities and over \$186.6 million in damages. Though Guam has not had a major declared disaster in the last two years, in 2015 they, along with CNMI, endured Typhoon Dolphin which was one of the most powerful tropical cyclones in the area since super Typhoon Pongsona in 2002. Typhoon Dolphin and Pongsona caused \$13 million and \$730 million (respectively) in damages, and each had at least one fatality. Guam also experiences earthquakes; recently four 5.0 magnitude or greater quakes were experienced over a two-day period in May 2018, and a 7.8-8.1 (differing measures) earthquake occurred in 1992. Guam is also threatened with nuclear missiles from North Korea. Following the tsunami in Japan a few years ago, Guam was on high alert for a tsunami.

Among the most significant disasters in the history of the US Territories in the past year were hurricanes Irma and Maria which took place in the summer of 2017. Hurricane Irma swept through the state of Florida and the Caribbean, including parts of Puerto Rico and US Virgin Islands. Collectively, Irma caused over \$630 billion in damages, which includes \$1 billion in Puerto Rico and \$2.4 billion in the US Virgin Islands. Less than two weeks later, Hurricane Maria devastated those areas of the Caribbean that had previously been spared by Irma. Unlike Irma, the entire island of Puerto Rico and St. Croix in the US Virgin Islands was impacted by Maria, including those areas recovering from Irma. The storm caused over a combined \$90 billion worth of damages in both islands with over 60 fatalities.¹ Maria caused so much devastation that it is now categorized in the top 3 costliest tropical cyclones in the US.²

During the interviews, interviewees mentioned numerous issues people with disabilities faced during and after these disasters occurred. Accessibility was one of the major issues children and adults with disabilities were faced with. While in shelters, people with disabilities who were on special diets for health reasons were unable to have access to those foods and had to eat what was provided at the shelter. Food insecurity after a disaster was a common theme among all of the Territories, which put people with disabilities in a vulnerable position either due to lack of prioritization and/or distribution of food not being accessible (for example, one interviewee discussed how water was being dropped out of a helicopter; those individuals without mobility they were unable to get access to the water). Nevertheless, the biggest obstacles for people with disabilities were the shelters. Shelters in all of Territories were accessible during a disaster, however most were unable to adequately accommodate the needs of people with disabilities (such as the ability to plug in medical equipment or providing parents/caretakers with an autistic child/adult a room or section with low stimulation). Also, people with disabilities may have been evacuated without their supportive assistive technology (AT) devices and aids. While facilities were accessible for their normal use; for example, as schools; for longer-term use as shelters these facilities were clearly inadequate for activities of daily living. Most facilities used as shelters did not have many if any showers, adequate restroom facilities to serve families and individuals with disabilities living in the shelters, and stable power and water necessary to support the large number of individuals housed at the shelters.

Though almost a year has gone by since both Irma and Maria struck the Caribbean,

both Puerto Rico and the US Virgin Islands are still recovering from the impact of the storms. Just recently, Puerto Rico had another power outage causing millions of residents to lose access to electricity. In a press release from September of 2017, delegates from the US Territories sent a letter to Congress seeking additional federal disaster relief funding for both Puerto Rico and US Virgin Islands, as well as adequate disaster relief funding for all Territories in the future.³ Territory delegates, as well as other delegates from the mainland, stressed the importance of Territories being given the similar funding for disaster relief as States in the mainland.

Typically, people with disabilities are more prone to have poorer health outcomes compared to people without disabilities. In this case, people with disabilities are more likely to have poorer outcomes after a disaster, due to being left behind or abandoned during evacuation in disasters, lack of preparation and planning, and inaccessible facilities and services.⁴ Also, people with disabilities are also likely to experience discrimination and be excluded from available resources based on disability.⁴ As stated earlier, US Territories are not given the same funding opportunities as States in the mainland for disaster relief, which means the funds they are receiving are inadequate even prior to disasters; further increasing the risk of people with disabilities receiving severely inadequate critically necessary resources and supplies after a disaster.

Lessons Learned: Emergency Preparedness, Response, and Recovery Themes

During the interviews with UCEDDs in the Territories, several themes emerged regarding emergency preparedness, response, and recovery. UCEDDs provided emergency preparedness trainings and

resources to the community, as well as to first responders. However, during the response and recovery phases, some UCEDDs felt there was a lack of communication between Territorial and local governments and the UCEDDs. Additionally, UCEDDs felt they were not always recognized for the unique skills and supports that they possess that might be tapped as first responders work to educate, evacuate, shelter, and help with recovery for individuals with disabilities. These communication failings played a role in all phases of emergency preparedness and response.

Theme 1. Preparedness

Prior to any of the disasters, UCEDDs in the Territories provided emergency preparedness training and resources to people with disabilities and their families, as well as other agencies in the community. UCEDDs created resources such as tip sheets and checklists to be handed to residents, in addition to providing trainings to first responders (emergency medical technicians (EMTs), paramedics, police officers, firefighters, etc.) on providing services to children and adults with disabilities during and after a disaster. In fact, the US Virgin Islands UCEDD incorporated people with disabilities in their trainings of first responders to assist with the delivery of content. The UCEDD in Guam disseminated packets with flashlights to people with disabilities in the community. The Guam UCEDD was able to partner with local agencies to cost share additional printing of copies of the resource materials, ads, and kits for dissemination to the community.

Theme 2. Partnerships

Each UCEDD partnered with local disability agencies and organizations during the emergency management phase in order to better support the disability community.

In the past, UCEDDs have partnered with agencies to create tools such as disability equipment, supply inventories, and registries. UCEDDs also strategized with disability agencies to know how people with disabilities were doing after a disaster and some were able to work in a liaison role to the Federal Emergency Management Agency (FEMA) to help identify key stakeholders in the community. UCEDDs in the Territories have great potential to be a stronger partner to Territorial and local governments as they seek to prepare for and respond to disasters moving forward. There was also a great deal of power for UCEDDs being in the AUCD network, where they felt they had voice to help bring awareness to the issues that were happening in their Territories, and where they were able to tap the national network for assistance, for shipment of needed assistive technology and durable medical equipment, and to access network donations.

Theme 3. Lack of Communication and Recognition

The response and recovery phases are often lead by Territorial and local and federal government personnel/agencies. During a disaster, some UCEDDs reached out to government agencies to provide assistance, however, they were not typically given an official role in the process of recovery and were often not included in any information sharing. Some UCEDDs expressed that there was a disconnect between their centers and Territorial and local governments, which had a negative impact on the response and recovery stages. It is not clear if those leading the emergency response and recovery efforts were unsure of how UCEDDs could be of assistance. Moving forward, it would greatly benefit both the recovery efforts and people with disabilities if these two groups worked together. Another barrier was the lack of coordination

or clear divisions of labor where several agencies were working on the same effort but did not communicate with one another. This caused some replications and even delays in provision of resources.

Moreover, in some of the Territories there were confusion among residents regarding how to access and qualify for FEMA assistance, and it was often difficult for them to get answers when needed. For example, residents were told to go online to apply for FEMA assistance, however they did not have access to the internet due to the loss of power and telephone connectivity.

Theme 4. Impact on People with Disabilities

Although all residents experience the impact of a large-scale disaster, children and adults with disabilities, as well as their families and caregivers, often experience more severe negative consequences during and after a disaster. Children and adults with disabilities who had to evacuate and stay in shelters experienced accessibility issues regarding bathing and hygiene, and access to medical needs. Though shelters in the Territories are required to comply with accessibility provisions in the Americans with Disabilities Act (ADA), they are not typically adequate for long term use and are unable to address many of the medical needs of people with disabilities. Other concerns that came up among both people with and without disabilities were employment, access to food and food assistance, and increase in illnesses.

Theme 5. Mental health

Perhaps the most concerning impact among residents in the Territories following a disaster are mental health concerns. It is common for there to be an increase in mental health challenges among residents, in the case of the latest major disasters. Residents, both with and without a disability,

showed increased rates of anxiety, suicide, intimate partner violence (IPV), and PTSD (post-traumatic stress disorder). Explanations for these increases can be due to several factors such as the magnitude of the disasters or factors such as having a pre-existing mental health disorder. In fact, people with mental health disorders are likely to be more affected by extreme weather events, and children are more impacted by disasters than adults and are more likely to have continued trauma-related symptoms after a disaster.⁵

First responders, emergency workers, and others involved with responding to extreme weather-related disasters are at increased risk to experience mental health problems connected to their experience responding to disasters.⁵ Several interviewees brought up the need for providers to practice self-care and that providers may need to ask for help from other agencies to assist. This would not only benefit the individual but allow for more productivity during recovery efforts.

Recommendations

Efforts can be made to better prepare our Territories and UCEDDs for future disasters and overcome the associated challenges and barriers. These recommendations and strategies may be utilized by UCEDDs both in the Territories and across the country to assist in overcoming barriers and challenges to improving emergency preparedness and response.

Recommendation 1. Building Capacity of Regional Disability Network

“Responding to people with disabilities should go beyond durable medical equipment.”

Capacity building among UCEDDs, government (at the Territorial, local, and

federal levels) agencies (such as local mayors, governors, and FEMA), and other disability agencies should take place prior to a disaster and non-emergencies. Regardless of size, one common factor for each UCEDD was the diverse partnerships with local agencies. UCEDDs should continue to strengthen those already established partnerships with Territorial and local governments and agencies in the disability network, as well as do an inventory to see whose input is missing and seek out partners to fill in those roles. They should also seek leaders in the disability community (including family leaders and leaders with a variety of disabilities) to provide their input in what resources children and adults with disabilities need regarding emergency preparedness, response, and recovery, and what barriers exist. It is critical that relationships are built and established prior to disaster to allow ample time for planning and strategizing, and that UCEDDs continue to increase their list of partners.

Recommendation 2. Create and Build on Relationship with FEMA

“There needs to be information sharing in the beginning and an agreement on what the role of UCEDDs could be during recovery.”

UCEDD and the Territory FEMA disability integration specialists should have an official partnership. The disability integration specialist should be aware, if they aren't already, of the role of UCEDDs in the disability community and work with them to identify needs and challenges of children and adults with disabilities during a disaster, and how to address them. One way for this to happen is for FEMA to share information with both UCEDDs and other disability agencies (such as Independent Living

Centers (ILCs) and Developmental Disability (DD) Network agencies like DD Councils and Protection and Advocacy agencies). These agencies typically have the resources to help. In addition to addressing the needs of people with disabilities, UCEDDs should also serve as cultural brokers and help assure that both FEMA and the disability integration specialist are aware of the cultural norms of the Territory and how FEMA can be aware and mindful of these cultural norms. For example, in some Territories when residents applied for FEMA assistance to help build their homes, many were denied due to not having the proper documentation to demonstrate ownership of their home and/or land. For most residents, properties were passed on from generation to generation and therefore there may not be a deed to the land that can be accessed. FEMA has the flexibility to be aware of and respond to these cultural practices and work with local agencies (such as mayors) to come up with solutions.

Lastly, increased educational campaigns on the functions and various programs and services offered by FEMA needs to be offered to residents, particularly for those residents with a disability or who have family member with a disability. AUCD currently has a Memorandum of Agreement (MOA) with FEMA; a recommendation would be for both organizations (including the Territory UCEDDs) to review and strengthen the MOA, and work together to create a fact sheet on the services FEMA provides, qualifications, and other important information. This can help educate residents in the Territories to be aware of necessary documents needed for FEMA assistance, and include them in their emergency preparedness kits. In addition, UCEDDs and FEMA can develop a resource list of Territory-specific disability resources that can be utilized during disaster and in recovery.

Recommendation 3. Utilization of UCEDDs in all Phases of Emergency Management

“UCEDDs and other disability agencies (i.e. DD Networks, Protection and Advocacy, etc.) should be present during the respond and recovery stages.”

Both AUCD and UCEDDs are positioned in unique roles to contribute to emergency preparedness, response, and recovery in the Territories, particularly in regard to the disability community. It is imperative that UCEDDs are not only included in the planning efforts but contribute their expertise to advise on how local government and agencies can better assist children and adults with disabilities before and after a disaster. Additionally, UCEDDs should have a role in every phase: Preparedness-UCEDDs that are capable should continue providing trainings and resources to people with disabilities in the community and to first responders; those centers that aren't able to provide trainings or resources can provide technical assistance to local government officials, including first responders. Response-UCEDDs can provide technical assistance to agencies like FEMA and local governments on the needs of people with disabilities, and how to assist them during a disaster. Recovery- just like the previous two phases, UCEDDs are able to serve multiple roles. They can assist with the recovery efforts and use their connections with other disability agencies to know where the needs are and how to assist. Mitigation- UCEDDs may assist with gathering information from people with disabilities, and families/ caretakers of people with disabilities, on their feedback on preparedness (i.e. how prepared they felt before the disaster, self-

efficacy, etc.) and experiences afterward (access to resources, shelters, etc.) and share those results with the necessary parties.

Finally, UCEDDs should advocate the need to recruit, hire, and retain people with disabilities, or family advocates, in disability emergency management positions to assure emergency management efforts are inclusive and accessible.

Recommendation 4. Intentional Regional Approach

“The needs of people with disabilities needed to be a priority after a disaster.”

It would benefit Territory UCEDDs to develop an Inclusive Emergency Management Taskforce for each Territory. To assure the right parties are present, representatives from Territorial and local governments (mayors from villages/cities, representative from the governor’s office, etc.), federal agencies (FEMA’s disability specialist or other personnel), disability agencies (UCEDDs, ILC, etc.), self-advocate or family advocate organizations, and any other individuals or agencies who would be helpful should be contacted. Each Territory’s Inclusive Emergency Management Taskforce should also create a communication chart outlining who to go to for information during a disaster; for example, if people with disabilities need to be identified in a region, UCEDDs and other disability agencies should be contacted.

Lastly, a Memorandum of Understanding (MOU) for emergency management should be created where the roles of each agency (and the contact person/title for said person) for emergency management should be explicitly identified. Also, the MOU should be revisited on a quarterly or yearly basis to be updated to capture changes in roles or personnel.

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