TESTIMONY OF THE CHAIRMAN OF THE NATIONAL COUNCIL ON DISABILITY, ANDRES J. GALLEGOS, ESQ., BEFORE THE U.S. COMMISSION ON CIVIL RIGHTS ON THE FEDERAL EMERGENCY MANAGEMENT AGENCY’S ROLE IN DISASTER PREPAREDNESS AND RESPONSE TO HURRICANES MARÍA IN PUERTO RICO AND HARVEY IN HOUSTON, TEXAS

June 25, 2021

Introduction

Chair Cantú, Commissioners, Ladies and Gentlemen, good afternoon. Thank you for the invitation to participate in this briefing.

The federal and local response, both in Puerto Rico and Houston, failed people with disabilities, with deadly consequences. People with disabilities in both Puerto Rico and Houston were not included in emergency planning prior to Hurricane María or Hurricane Harvey. They were excluded from accessing much of the disaster relief provided in their aftermath. Not only were they failed by the governmental response, but by many of the nonprofit organizations supplementing those relief efforts. In addition, there was a notable disparate federal response to Hurricane María as compared to the federal response to Hurricane Harvey.

Since the Post-Katrina Emergency Management Reform Act of 2006 (PKEMRA)\(^1\) required the National Council on Disability (NCD) and the Federal Emergency Management Agency (FEMA) to work closely with each other to improve the outcomes of persons with disabilities before, during and after major disasters, NCD has served as a liaison within the disability community and FEMA in working to achieve that goal. My

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comments here are informed by meetings and discussions with the disability community in which they voiced concerns regarding these issues.\textsuperscript{2}

While today’s briefing will focus on discrete aspects of FEMA’s response to these natural disasters, as it pertains to Puerto Rico, I believe it is important that we understand the plight of people with disabilities residing on the island before September 2017. That’s important to better understand why they were so vulnerable to the effects of the hurricane, and why greater efforts to address their needs in recovery was required. We are talking about the needs of approximately 687,000 people, representing approximately 21.7% of the island’s population.\textsuperscript{3}

\textit{The Plight of People with Disabilities Residing in Puerto Rico before Hurricane María}

People with disabilities residing on the island were vulnerable to the effects of Hurricane María. Their vulnerability was predictable given the shaky infrastructure supporting their needs prior to the Hurricane. Please note - their vulnerability was not predictable because of the existence of their disabilities, or disability \textit{per se}, but because of the environmental, societal and political infrastructure of the island.

There was significant economic vulnerability as a result of the island’s economic condition and disparate treatment in federal benefit programs. The island’s economic posture was

\textsuperscript{2} NCD visited Puerto Rico in May 2019. We conducted a town hall in the city of Humacao, attended by over 150 people. There we listened to the concerns of the residents with disabilities and heard firsthand of their struggles on the island before, during and after Hurricane María. The next day we held our Council meeting in San Juan wherein we also listened to testimony from more people with disabilities and their families. We also heard from the Puerto Rico Disability Community Relief Network (see footnote 12 \textit{infra}); the island’s Secretary of Housing and the executive director of the Puerto Rico Planning Board who spoke about the island’s recovery efforts. As a result of that visit, NCD undertook a study on what it means to be a person with a disability in Puerto Rico. The report, titled \textit{Disparate Treatment of Puerto Rico Residents with Disabilities in Federal Programs and Benefits} — is now in the editing stage, and after we have it translated into Spanish, we anticipate its release in September or October.

bleak coming into 2017. It had been facing a recession and job losses since 2006. It had filed for the equivalent of federal bankruptcy protection in May 2017. In the decade preceding María, Puerto Rico lost 10% of its population, mainly professionals, deepening the economic crisis because the loss of tax revenue. More than 45% of the island’s population lived below the federal poverty level (more than three times the US national poverty rate). The unemployment rate was just over 18%, more than twice that of the United States and nearly 8% higher than Mississippi at that time. In 2017, the poverty rate was 48% among working aged people with disabilities. The employment rate for working aged people with disabilities was 23.5%.

The Supplemental Security Income (SSI) program is arguably the single most important safety net program in the United States for people with disabilities. Puerto Ricans living on the island are ineligible for SSI benefits. Instead, they receive benefits under the predecessor to the SSI program, the Aid to the Aged, Blind and Disabled Program (AABD). AABD, however, is not a substitute for SSI. It provides significantly lower benefits. Today the maximum monthly SSI benefit is $741, whereas the maximum monthly AABD benefit is $75.

Moreover, there was significant food insecurity. The Supplemental Nutrition Assistance Program (SNAP) provides nutrition assistance to eligible, low-income individuals and households in need. SNAP is available in all 50 states, the District of Columbia, Guam and the US Virgin Islands. It is not available in Puerto Rico. Instead, Puerto Rico receives

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4 Nathan Bomey, Puerto Rico: 6 reasons why the island slid into financial crisis (usatoday.com) (October 4, 2017)
6 Department of Agriculture, Examination of Cash Nutrition Assistance Program Benefits in Puerto Rico (August 2015) PUERTO RICO REPORT FINAL 081215.pdf (azureedge.net)
7 Id.
8 Committee on Ways and Means, U.S. House of Representatives, Green Book, Background Material and Data on the Programs within the Jurisdiction of the Committee on Ways and Means. Appendix B: Social Welfare Programs in the Territories | Green Book. House Committee on Ways and Means.
9 Social Security Administration, Nutrition Assistant Programs, (June 2019). Nutrition Assistance Programs (ssa.gov)
a block grant for nutritional assistance to fund its own Nutrition Assistance Program (NAP). SNAP benefits are larger than NAP benefits and the criteria to qualify for SNAP are lower than that for NAP.

The health care system also faced challenges, mainly because it was underfunded. Unlike the 50 US states and Washington, DC, Medicaid spending in Puerto Rico has been subject to a statutory annual cap. The scope of the island’s Medicaid program itself is severely limited. Puerto Rico’s Medicaid program does not cover home health services, hospice care, medical equipment and supplies or nursing facility services. Many residents of Puerto Rico access primary health care services through one of 93 community health centers, which rely heavily on federal Medicaid funding.

The high unemployment rates, the poverty levels, the disparate treatment in federal programs, limited access to health care, and the underfunding and limited scope of Medicaid, all contributed to a low degree of resiliency in the ability of Puerto Rican residents with disabilities to respond to the effects of Hurricane María. Given all of the foregoing, when Hurricane María blew onto the shores of Puerto Rico, the disaster was magnified for its residents with disabilities.

The Effects of Hurricane María on People with Disabilities Residing in Puerto Rico and its Aftermath

10 Kaiser Family Foundation. Puerto Rico: Medicaid, Fiscal Issues and the Zika Challenge. September 27, 2016. https://www.kff.org/medicaid/fact-sheet/puerto-rico-medicaid-fiscal-issues-and-the-zika-challenge/. See also, Committee on Ways and Means, U.S. House of Representatives, Green Book, note 12 supra, Section 1108 the Social Security Act places a ceiling on the total amount of annual grant funding that may be awarded by the Department of Health and Human Services for certain programs to the territories, with the exception of the Northern Mariana Islands.


Hurricane Maria had significantly damaged key transportation, communication, and electricity infrastructure across the island, which in turn exacerbated already challenged health conditions. Immediately after the hurricane, there was virtually no electricity, available water, or transportation access on the island. Many island residents had difficulties accessing groceries and fresh food, relying on meals provided by FEMA, the Red Cross, World Central Kitchen, and other entities. Right after the storm, access to water was minimal, with water treatment and pumping stations knocked out by the storm. Hospitals and other health care infrastructure suffered extensive damage from the storm, and most hospitals were left without electricity and with limited access to generators with fuel.

As reported by the Puerto Rico Disability Community Relief Network, in the aftermath of Hurricane María:

- There was only one fully accessible centralized shelter for people with disabilities on the island. That shelter, housed in the San Juan Convention Center and co-located with the Emergency Response Central Command Center, was immediately evacuated after Hurricane María struck as it lost power and those who sought shelter there were bussed to other less accessible shelters.

- Schools used for shelters in the 78 municipalities were physically accessible in that they had ramps for wheelchair access, but did not have accessible sleeping areas, accessible showers, medical assistance, medical supplies, alternate power or sign language interpreters. None of those shelters were equipped to address the needs of persons with intellectual or developmental disabilities.

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13 The Puerto Rico Disability Community Relief Network (PRDCRN) started as an ad hoc grassroots coalition then consisting of a handful of bad ass women who saw the feeble response of the island’s government and FEMA in addressing the needs of people with disabilities. They took it upon themselves to raise funds to buy supplies for the island’s disability community. Through their efforts, they were able to assist 9,500 families and 68 of the 78 island’s municipalities. Today, its members include La Defensoría de las Personas con Impedimentos; Movimiento para el Alcance de Vida Independiente; Puerto Rico Council in Developmental Disability; Puerto Rico Assistive Technology Program; and the University Center for Education on Developmental Disabilities. PRDCRN is supported by the Clinton Foundation. CGI Commitment: Puerto Rico Disability Community Relief Network (PRDCRN) | Clinton Foundation
• Many shelters had no electricity, which adversely affected people with mobility disabilities that utilized powered mobility devices. Moreover, persons insulin dependent had no cool storage space and consequently lost their insulin.

• There was only one radio station operable during and immediately after the hurricane, which detrimentally affected the Deaf population, who struggled to learn of any organized response efforts or services available to assist them. The government began to transmit live news conferences about one – two weeks after the hurricane, which had sign language interpreters, but most of the island’s Deaf population could not watch as there was no electricity and no television cable.

• Immediate response efforts were concentrated in a central location within each of the 78 municipalities. To receive any of the supplies or services offered there, people were required to somehow get there. Consequently, people with disabilities went without food and water for days and weeks.

• Many people with disabilities lost assistive equipment during the hurricane. Insurance plans denied replacements. FEMA was slow in providing them because it required survivors’ insurance plan denial. Most suppliers of assistive equipment on the island were not open for business because of their own losses. As a result, many people with disabilities had no wheelchairs, hearing aids or other assistive devices for their daily living.

• Family members, many of whom are the sole caregivers of bedridden people with disabilities, were forced to leave their homes in search of supplies or to coordinate disaster aid, leaving their disabled loved one’s alone and unattended, some for hours at a time.

• People with disabilities that required medical equipment 24/7 were required to purchase generators to sustain their lives. However, those generators were not designed to run 24/7. Consequently, many broke down requiring families to use what little funds they had to purchase additional generators and gasoline.

• Emergency food supplies that were being distributed were often high in sodium and not suitable for the dietary needs of many people with disabilities.

As reported by The Partnership for Inclusive Disaster Strategies in its May 2018 report – Getting It Wrong: An Indictment with a Blueprint for Getting It Right, Disability Rights,
Obligations and Responsibilities Before, During and After Disasters\textsuperscript{14} – which is an after action report, principally authored by Ms. Marcie Roth,\textsuperscript{15} a global expert on whole community inclusive emergency and disaster response, recovery and mitigation:

- People with disabilities were turned away from both general and special needs shelters. Reasons reported included power dependence, personal assistance services requirements, service animals, need for bariatric equipment, mental health conditions, chemical sensitivities, autism and need for support due to cognitive or intellectual disabilities. It is reported that many of these individuals were diverted to hospitals or long-term care facilities when they did not need a more restrictive environment but simply needed equal access. Key informants in Puerto Rico reported that hospitals had become de facto shelters for people with disabilities who did not require hospitalization.\textsuperscript{16}

- Disaster survivors with disabilities did not have equal access to the FEMA application process. Some people with disabilities could not leave their homes to get to sites where they could apply for FEMA. The reasons ranged from the fact that they were power dependent and needed life-saving equipment in order to leave; roads were blocked, and they were unable to traverse them in wheelchairs or they lacked conventional or accessible transportation to get to the site. Those who were able to get to the site to apply for FEMA encountered additional barriers to equal access.\textsuperscript{17}

- Supplemental oxygen was denied to thousands of disaster survivors living in the community in Puerto Rico. When HHS was repeatedly pressed to address this urgent need, they were unable to identify the accountable senior executive responsible for the solution, leaving many disaster survivors without access to oxygen. This was further exacerbated when the USNS Comfort was identified as a potential provider, however oxygen was not supplied. Further, a protocol for patient admission and care was never communicated to medical providers and

\textsuperscript{14} The Partnership for Inclusive Disaster Strategies, Getting it Wrong: An Indictment with a Blueprint for Getting it Right, Disability Rights, Obligations and Responsibilities Before, during and After Disasters. 2017-2018 After Action Report – The Partnership (disasterstrategies.org)

\textsuperscript{15} Ms. Roth served a presidential appointment to the U.S Department of Homeland Security Federal Emergency Management Agency from 2009 to 2017, serving as Senior Advisor to the Administrator and congressionally mandated Disability Coordinator for the agency. While at FEMA, she established the Office of Disability Integration and Coordination (ODIC), serving as its Director. Under her leadership, ODIC led national transformation towards integrating the access and functional needs of the whole community throughout emergency preparedness and disaster response, recovery and mitigation.

\textsuperscript{16} Id. at 103.

\textsuperscript{17} Id., at 51.
disaster survivors needing the urgent care that deployment of the Comfort promised.\textsuperscript{18}

- The disasters caused services delivered to people with disabilities to maintain their health to be interrupted, delayed and in some instances, discontinued. Interruption of services was particularly significant in Puerto Rico, where service providers had evacuated and were permanently relocating. Key informants from Puerto Rico reported that the number of health professionals and caregivers who evacuated from the island was disproportionately impacting children and adults with disabilities who require physical, occupational, speech, psychological and other therapy and for personal assistance with activities of daily living.\textsuperscript{19}

- Many individuals and families were forced to make difficult decisions about evacuation. The complexities of these decisions were highlighted by a group of families in Puerto Rico whose children were on life support and required uninterrupted power. Many of these children were not hospitalized before the hurricane, but when the power was interrupted, they evacuated to local medical facilities. When these facilities were unable to provide adequate power, the children were evacuated to the Children’s Hospital in San Juan. When it became clear that this hospital was also having difficulties with power, doctors reached out to colleagues on the mainland who arranged to evacuate the children to Florida and other destinations.\textsuperscript{20}

- Residents of Puerto Rico had to apply for Medicaid in the state they evacuated to, even if they had Medicaid already. This caused delay in medical services for people with disabilities in many instances and ignited a political firestorm over the financial responsibility for evacuees.\textsuperscript{21}

\textsuperscript{18} Id., at 67. One of the gaps that was repeatedly raised but never resolved was the provision of oxygen to disaster survivors in Puerto Rico who were not in acute medical settings. Reportedly, there were over 50,000 individuals living in the community across Puerto Rico who use oxygen for maintaining their health and independence. Oxygen was previously manufactured and supplied on the island and provided to residents. When the manufacturing capability was indefinitely disrupted, there was no plan for providing an alternative source of oxygen. This critical life-saving and life-sustaining need seemed to fall squarely within the responsibility of FEMA’s Emergency Support Function \# 8, Public Health and Medical Services, however the focus of all of the Office of the Assistant Sec. for Preparedness and Response’s efforts were on establishing hospital and medical facility operations, leaving no clear lead for meeting the health maintenance needs of thousands of disaster survivors who depend on receiving oxygen outside of medical facilities. When the US Naval Ship Comfort arrived, it was assumed that their oxygen manufacturing capability would be utilized to meet these unmet needs, however it quickly became apparent that the hospital ship was only providing oxygen for facility-based care, further eliminating any immediate resources for non-institutional provision to disaster survivors with disabilities. While it is unclear what the outcome was for these individuals, it has to be assumed that the absence of oxygen was not compatible with survival.

\textsuperscript{19} Id. at 68.

\textsuperscript{20} Id. at 102.

\textsuperscript{21} Id.
By failing to ensure access to disaster relief services, FEMA violated the rights guaranteed to individuals with disabilities under the federal nondiscrimination laws, namely the Americans with Disabilities Act\textsuperscript{22} and the Rehabilitation Act of 1973.\textsuperscript{23} That was clearly noted on October 25, 2017, when the U.S. House of Representatives Committee on Homeland Security, wrote to FEMA’s acting secretary requesting answers as to why the civil rights of people with disabilities were not protected during the response to Hurricane María. The letter accused the Department of Homeland Security and FEMA of playing "hot potato" with their responsibilities to protect the civil rights of disaster survivors, pointing out that people with disabilities were paying the price. The letter states, in part:

… Since Hurricane Maria struck Puerto Rico, people with disabilities have been denied clean water or provided dirty water, provided expired canned foods, excluded from FEMA applicant services, excluded from access to medical care, and denied accessible toilets and showers. We have heard reports that people with disabilities have been turned away from shelters and that shelters do not have trained personnel or medical supplies. Moreover, the Federal government has failed to communicate information about alerts, warnings, evacuations, medical care, sheltering, and the provision of commodities in a manner accessible to individuals with hearing impairments or other disabilities. Finally, the Federal government is failing to provide assistance to homebound people who need fuel for generators to power oxygen tanks and refrigerate medicine. This is unacceptable.\textsuperscript{24}

The letter went on to question why this was allowed to happen, pointing out that after the Post Katrina Emergency Management Reform Act, among other things, authorized the position of Disability Coordinator within FEMA, a position charged to reviewing disaster response plans, including evacuation routes and transportation options, and are made

\textsuperscript{22} The Americans with Disabilities, 42 U.S.C. § 12131, \textit{et seq.}


known to individuals with disabilities, among other things, like identifying critical gaps the populations with special needs in concert with state and local governments. However, FEMA was without a permanent Disability Coordinator for better part of the year.\textsuperscript{25}

\textit{Discrimination of People with Disabilities in the Federal Response to Hurricane Harvey}

The discrimination against people with disabilities in the federal response was not isolated people with disabilities residing in Puerto Rico. People with disabilities residing in Houston faced similar occurrences of discrimination. The National Council on Independent Living, on November 7, 2017, issued a report - Emergency Management Challenges and Failures for People with Disabilities in Texas during Hurricane Harvey.\textsuperscript{26} Among the most significant findings:

- People with disabilities encountered the most barriers and problems during application for assistance from FEMA.

- There was a disturbing trend of people with disabilities who had lived in the community being transferred to institutional settings, either due to lack of post-shelter housing options or due to the difficulties of navigating disaster recovery.

- Among nearly all the submitted reports, there were significant problems with communication between emergency services and people with disabilities, which show that emergency services may need to become better educated on how to interact with people with disabilities and learn about making information accessible.

- Although there are many different routes that could be taken to fix the problems detailed in [the NCIL report], there is an overarching necessity for emergency management and response organizations and disability advocacy organizations

\textsuperscript{25} \textit{Id. at 117.}
\textsuperscript{26} Appendix C to The Partnership for Inclusive Disaster Strategies, Getting it Wrong: An Indictment with a Blueprint for Getting it Right, Disability Rights, Obligations and Responsibilities Before, During and After Disasters. 2017-2018 After Action Report – The Partnership (disasterstrategies.org)
to proactively work together before crises occur to anticipate and meet the needs of people with disabilities in emergency situations.

The report further pointed out that in many cases, the resistance of governments toward making comprehensive and proactive emergency plans for people with disabilities has only been solved by painstaking, complex litigation. In 2011, a court ruled that the City of Los Angeles violated the Americans with Disabilities Act by "failing to meet the needs of its residents with mobility, vision, hearing, mental, and cognitive disabilities in planning for disasters." 27 Another example of this litigation was *Brooklyn Center for Independence of the Disabled v. Mayor Bloomberg*. 28 Filed more than a decade after September 11th, 2001, and during the time of disasters such as Hurricanes Irene and Sandy, the Court found that New York City had discriminated against people with disabilities by failing to plan for their needs in large-scale disaster situations. This ruling led to a settlement between parties that required the city to make improvements to their emergency management planning for people with disabilities in all major affected programs and services, including transportation, evacuation from high rises, and sheltering.

**Disparities in the Federal Response to Hurricane María and Hurricane Harvey**

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27 *Communities Actively Living Indep. & Free v. City of Los Angeles*, No. CV 09-0287 CBM (RZX), 2009 WL 10676002, at *1 (C.D. Cal. June 1, 2009)

There was a notable disparate response by the federal government in addressing the needs of the survivors of Hurricane Maríá in Puerto Rico and Hurricane Harvey in Texas. For example:

- Within the first 9 days after Hurricane Harvey hit, survivors already had received nearly $100 million in FEMA dollars awarded to individuals and families, whereas survivors in Puerto Rico had only received slightly over $6 million in recovery aid.

- Within the first two months post landfall, Harvey’s survivors received nearly $1 billion. Maríá funds did not hit $1 billion until four months after landfall.

- Within 9 days of landfall, there were 30,000 federal employees posted in Texas, whereas only 10,000 were posted in Puerto Rico. At the peak, 19,000 federal employees were posted in Puerto Rico one month after landfall. At the peak in Texas, 31,000 employees were posted.

- Blue roof tarps were not requested in Houston as residents received temporary housing relief, whereas in Puerto Rico 25 days after the storm only 260 of the 60,000 blue tarps requested had been provided and installed.

- Within the first nine days of landfall in Houston FEMA provided 5.1 million meals, 4.5 million liters of water, whereas in Puerto Rico, FEMA provided 1.6 million meals and 2.8 million liters of water.

- In Houston, $15.25 billion funding package was provided through a combination of FEMA funding ($7.4 billion); Small Business Administration Disaster Loan Program ($450 million); HUD Housing Assistance ($7.4 billion); and $5.5 billion in tax relief for Texans impacted by Hurricane Harvey. President Trump signed a bill authorizing a tax deduction for property damage costs and allowed penalty free access to retirement savings without penalties. Nothing comparable for Puerto Rico.

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FEMA provided less aid to Puerto Rico than to other states affected by hurricanes. In addition, FEMA rejected over half of FEMA applications for assistance made by Puerto Ricans. Thousands of Puerto Ricans were forced to leave the island and moved to the southeastern United States in search of better living conditions. However, Puerto Rican Medicaid beneficiaries that relocated had to apply for Medicaid in the state where they sought refuge as their Medicaid benefits in Puerto Rico were not portable. The lack of Medicaid coverage placed persons with disabilities at a high risk of worsening health conditions, with the greater risk of institutionalization.

**Conclusion**

In both Texas and Puerto Rico people with disabilities were failed by their government. The pre-existing shaky economic, environmental and political infrastructure in Puerto Rico, including decades of disparity between Puerto Rican residents and their counterparts in the mainland with respect to their eligibility for and the receipt of benefits under certain federal programs, exacerbated the damage caused by Hurricane María. Those pre-existing conditions and that disparity adversely affected people with disabilities the greatest given their vulnerability, vulnerability not because of disability, but simply because of where they reside.

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