



**US Department of Homeland Security (DHS)
Office for Civil Rights and Civil Liberties
Listening Session Recap, San Juan, Puerto Rico
May 15, 2018**

I. Introduction

With the support of FEMA's Lead Disability Integration Advisor, DHS hosted a listening session at the San Juan Sheraton Convention Center. In attendance were representatives of non-governmental organizations, service providers, community members, and representatives of several municipalities. Federal government partners representing the DHS Office for Civil Rights and Civil Liberties (CRCL) and Federal Emergency Management Agency (FEMA) included:

- Cameron Quinn, DHS Officer for CRCL
- Linda Mastandrea, Director, FEMA Office of Disability Integration and Coordination (ODIC)
- Regis Phelan, Acting Director, FEMA Office of Equal Rights (OER)
- Madeleine Goldfarb, FEMA Lead Disability Integration Advisor
- Rebekah Tosado, Section Chief, CRCL

The listening session began with Rebekah Tosado of CRCL welcoming attendees, providing emergency exit information, and announcing the presence of sign language and Spanish-English interpreters. Ms. Tosado thanked Ms. Goldfarb for her role in assisting with the listening session and for all her work in Puerto Rico, with the Commonwealth, municipalities, and partners on the Island PR. Ms. Goldfarb stated she felt privileged to work with the Puerto Rico organizations and partners. She emphasized the importance of hearing their stories to help rebuild Puerto Rico and ensuring that the people with disabilities in Puerto Rico have a seat at the table.

Officer Quinn thanked Mike Byrne, FEMA's Federal Coordinator Officer, for welcoming and meeting with us. She mentioned her prior experiences working in Puerto Rico and getting to know Puerto Rico. She expressed her hopes that the meeting would result in better planning by the government for the disability community and that the needs of persons with disabilities are integrated into planning efforts. Officer Quinn explained that

the purpose of the meeting was to hear about concerns and experiences related to the impact of the disaster had on individuals with disabilities and the surrounding areas. She asked that participants also share “what worked,” or effective practices. By better understanding these experiences, and in partnership with the state and local entities, including non-profit organizations, she noted that we can do more to improve preparedness, response, and recovery for persons with disabilities in time for the next hurricane season and other disasters.

Officer Quinn explained that CRCL has jurisdiction to investigate disability-related complaints alleging violations of Section 504 of the Rehabilitation Act of 1973, as well as under CRCL’s statutory authority, 6 USC 345.

These investigations provide CRCL a powerful avenue to make meaningful and timely policy changes and in many instances to resolve the specific issue raised. However, the office’s ability to conduct investigations depends on hearing from individuals who have such allegations making us aware of their specific concerns. Officer Quinn provided the email address to file complaints (CRCLCompliance@hq.dhs.gov) and encouraged attendees to share the information with other community members and constituents who may wish to file complaints.

In conclusion, Officer Quinn explained that she wanted to hear from individuals about their concerns but also about what worked well. She explained that we can build off of things that went well and share good practices not just in Puerto Rico but in other places around the United States.

II. Issues/Concerns, Comments, and Effective Practices Noted

A. Communication Access for People with Disabilities

- **Planning Efforts Should Take into Account that Power and Communication May be Down** - Communication was an issue for everyone across the island. There was no type of communication and this was even more impactful for the deaf population. Due to the hurricane, there were no news stations and no electricity for people to see what was going on. The only thing working was radio and there was only one radio station functioning across the whole island.
- **Planning Should Take into Consideration the Needs of the Deaf Community** - The lack of communication was a significant issue for the

deaf population in Puerto Rico. Community members told us that many in the deaf community had no idea what was going on, or where the shelters were before the storm. Some of them were not accustomed to watching news channels because these news channels are not accessible on a day-to-day basis. Once the hurricane hit, there was no way for community members to reach family members or others. Many in the deaf community didn't know where they could go get help or where the distribution sites for food and supplies were. They had no idea where they could access healthcare.

- **It is the Government's¹ Responsibility—not the Families'—to Communicate about Emergencies to the Deaf Communities** - A community member told us that there is a culture of expecting that family members who are hearing will explain to deaf persons what is happening in an emergency but it is the government's job to provide information about the emergency, including information on sheltering in every emergency.
- **Government Agencies and Medical Providers Should Ensure that they can Communicate with the Deaf Population** – A community member told us that there is “not one agency” in Puerto Rico that can communicate with deaf persons. The community member asked how these agencies are going to offer services when they cannot communicate with persons who are deaf. Other comments made on this topic include:
 - It is important to consider that there are different kinds of sign language in Puerto Rico. There is a need to have a deaf interpreter that can understand “our kind of sign language.” Another community member recommended having funds to hold press conferences with the different kinds of sign languages from the different regions of the island so that every deaf person can understand what is being said.
 - There was only one hospital open in one of the regions but at that one working hospital there were no interpreters available.

¹ The Government” or “Governments” as used in this document refers to federal, territorial, or municipal governments, depending upon which of these entities has a role or responsibilities in the area described.

- For these reasons it is important that before, during, and after the hurricane it is very important to be prepared and have a program for persons who are deaf so that deaf individuals can be prepared.
- **The Government Should Make Improvements to the Text to 911 Program** - In some cases, when trying to text 911, there was no response. In other cases, the response was that the deaf person had to actually call 911. There needs to be training of 911 operators to be able to take text messages from the deaf community in the correct manner.
- **The Government Should be Prepared to Communicate with People Who Have Other Disabilities** - One community member said that there are other disabilities that cause obstacles for communication and that adequate communication can be the difference between life and death. For blind people when information is provided through images this is a problem. Autism and other conditions that cause obstacles in oral communication must also be considered.
- **The Government Should Consider the Transportation Needs of Persons with Disabilities in a Disaster** - The lack of transportation after the hurricane made things worse for people with disabilities.
- **The Government Should Ensure it Provides Accessible messaging when communicating about a possible breach of the Guajataca Dam** - There were challenges associated with informing people in the area of the dam that there could be a breach. There was no consideration for how people with disabilities would find out that the dam might breach. This is relevant not only for those who are deaf but for isolated communities.
- **Effective practice: FEMA, MAVI (*Movimiento para el Alcance de Vida Independiente*/Center for Independent Living), and the Red Cross partnered to reach the deaf community** – A MAVI representative spoke about efforts to contact people in the deaf community through schools and other means. They did so across different regions and made a list of those who had needs. By doing so they were able to identify needs and get food and personal items to these communities, which they did with the support of FEMA and the Red Cross. The organization made in-person contacts to support this

community.

- **Communication with the Elderly and Persons with Conditions Like Alzheimer's Needs to Improve** – There were challenges in communicating with the elderly and people with Alzheimer's. Communication with these populations has to be explicit and gentle.

B. Preparedness and Evacuation

- **The Government and Community Partners Should Establish a Network of Contacts before a Disaster Strikes** - There is a need to pre-establish contacts in the community in order to better respond and provide services for people with disabilities. One participant stressed the need to have a collaboration with many sectors of the community, for example, church congregations, community centers, and schools, and that there should be an understanding that these are the contacts that know where homebound persons and persons with needs are.
 - **Effective practice: Roster of Community Leaders** - One organization stated that it had done a lot of work putting together a roster of community leaders, pastors, and other community contacts. This kind of work and communication among contacts should be pre-established so that in a disaster people can be dispatched to provide support including in the most isolated areas.
- **The Government Should Identify Those who Need Assistance before an Emergency** - The Puerto Rico Health Department through *la Reforma* should have the information on people with disabilities and any type of special needs they might need. The Health Department made an effort to develop a registry a few years ago, however, it appears the list was deactivated. A community member asked what happened to the data that was compiled at that time and if there was a new effort to have such a list.
- **Municipalities Should have a Role in Identifying Those Who Need Assistance** - Several community members said the municipalities are a good starting point for compiling the information about those who have the most needs in the community. In her municipality there were concerted efforts to work with those with disabilities and she offered to

support other municipalities through technical assistance and training.

- In one municipality there was an effort to write down the needs of survivors, however, the municipality wasn't taking down information on those who had disabilities. Therefore, the organizations quickly made note of that and addressed it.
- Each municipality should have a group that is responsible for being aware of these problems whether it is a lack of food or electrical problems.
- We heard from several community members that one of the toughest jobs is identifying where those families with family members who are deaf, have intellectual disabilities, or have other needs are. None of the municipalities on the island had information about where these families were living in order to target resources to them.
- **Government Agencies Should Improve Planning, Including Planning for Interagency Communication** - A community member said that agencies should look at their plans, specifically they should review what did not work and make improvements based on that. There should also be better plans for how agencies communicate with one another during a disaster.
- **The Government Should Work with More Organizations that Provide Services to the Elderly and to Persons with Alzheimer's** - One organization representative told us that since the day after Hurricane Maria her staff was available to provide therapy using social workers and psychologists. However, it was difficult to connect to where the need was and provide those services. There were barriers to providing this kind of help.
- **FEMA Should Partner with More Non-profit Organizations** - One community member urged FEMA to include non-profit organizations in its response efforts saying that the non-profit organizations are FEMA's best allies since it is these organizations, not the government, that know who needs help.

- **Puerto Rico Should Have a Comprehensive Oxygen Plan –** A number of participants said that oxygen distribution was a significant problem. The normal suppliers of oxygen didn't have any to distribute. People would try to go to the USNS Comfort to get it and would be turned away because the Comfort did not carry oxygen. Organization representatives told us there is a need for a plan to take care of the needs of persons who rely on oxygen. The companies that normally supplied oxygen could not help refill the tanks. To this day, the community does not know if something like this happens again how they are going to take care of this problem.
 - **Identifying who Needs Oxygen –** A participant suggested that as far as identifying who needs oxygen this could be easily solved by going to those companies that are suppliers of oxygen/ oxygen tanks since it's these companies that normally fill the supply needs.

- **Hospitals Should be Better Prepared for Emergencies -** A community member explained that hospitals in Puerto Rico were not prepared. This had a big impact on the response to the hurricane. Some hospitals discharged patients who would not have been discharged because they were not prepared to serve them.

- **The Government Should Support Families of Children with Disabilities -** One participant said that family members of children with disabilities who were hospitalized were in a difficult situation and these families' needs also have to be considered. After the hurricane, family members had to stay in the parking lots of hospitals where their children were being treated. In one case, the USNS Comfort would provide care to the child but the parents were not allowed and so refused access to ship for the child. It's important to identify this population of parents and families and recognize that they need help so that services can be offered to them. They should be offered space whether it be in a shelter or emergency ship.

- **The Government Should Consider Dietary Needs When Distributing Food -** In an emergency situation it is understood that you can't be too picky; however, for some people who have disabilities, certain foods can worsen the condition and even lead to death. Some of the food being distributed was full of sugar or sodium. Even though there was

packaging information, those who cannot read and write would not be able to understand the information.

- **The Government Should Plan for Getting Food to Those Who Cannot Make it to a Distribution Centers and Prioritize Food Distribution** - People were told that food would be distributed in the town square but people with disabilities were often too far from those points or it was too difficult for them to make the long lines. There should be a way to prioritize who gets the food, whether or not the person has a disability.

- **The Government Should Plan for the Evacuation of People Who Live in High Rise Buildings** - There should be plans for assisting those who live in high rise buildings. People who live in apartments on high floors didn't have a way to get down. They were never visited by FEMA.

- **The Government Should Have Better Plans for Meeting the Needs of People with Disabilities** - A participant offered comprehensive comments about meeting the needs of persons with disabilities, including:
 - It is important to support the families of people with disabilities, for example, by helping them with provisions of special food for those who have special diets, and medications for those who have medical conditions.
 - It is also very important that these families have generators that will provide electricity for equipment that is needed to sustain life.
 - It is very important to train first responders so that they are aware of the mental health conditions and the very sensitive task of evacuating this population.
 - It is important to establish a registry of volunteers that can help people with disabilities; these group of volunteers could support FEMA.
 - It is important to acquire special equipment for first responders to assist in evacuating people with significant disabilities.
 - It is important to plan to respond to individual needs of persons with disabilities in evacuation rather than rely on a one-size fits all approach (e.g., persons with Alzheimer's were restrained without consideration of their individual needs).

- **The Government Should Have a Greater Role in Providing Generators, Gas, and other Supports and Prioritize Who Gets These** - There were many situations where families depended on a generator to power equipment. In some cases, having access to the generators wasn't the problem, rather it was having the money to buy gas for the medical equipment or the problem was having to stand in line for hours to buy gas. The community member suggested creating a list to identify people who needed quicker access to gas. In some cases, families had to jump through hoops to get certification from an electrician before being given a generator.
- **The Government Should Plan to Meet the Needs of People who Require dialysis and Rely on Feeding Machines or Ventilators** - There is a need to evaluate the needs of people who require dialysis and children who rely on feeding machines or ventilators. It may be helpful to create specialized centers where families can go and get treatment for their family members.
- **The Government Should Plan to Provide Durable Medical Equipment** – A community member told us about cases of people using motorized wheelchairs where the batteries had been damaged and where finding a replacement was very difficult. To this day there are people who do not have wheelchairs.
- **The Government Should Plan to Meet the Needs of the Homeless Population** – A community member stated that it is important that there be preparedness efforts focused on the needs of people who are homeless. It is important to clearly identify what their needs are, including their medical and mental health needs, and to have a plan to distribute resources to this population.
- **Community Emergency Response Teams (CERT) Should be Activated and Include People with Disabilities** - A community member spoke about the value of CERTS and that these should include people with disabilities.
- **The Government Should be Prepared to Provide Durable Medical Equipment and Ensure that Shipments of Such Supplies Promptly Reach the Intended Beneficiaries** - Maria Town, the Director of the Houston's Mayor's Office of People with Disabilities and the Seafarers

International Union held a collection drive for Durable Medical Equipment (wheelchairs, crutches, walkers, canes, etc.) in Houston. These supplies arrived in Puerto Rico in October 2017, however, they remained at the port for many months despite the needs of the community. Disability organizations finally secured a release from Hacienda; however, the organizations were told in March of 2018 that the shipment could not be released to them until they made a payment of \$12,000 in storage fees at the port. The organizations had involved all levels of government until the president of the company storing the goods, National Shipping Agencies, released the shipment at no cost upon learning that it had been held up at the port for so long. The president stated that he had not realized that the container had been detained for such a long period due to “red tape” of clearing goods and that National Shipping had provided their services to the SIU on a humanitarian basis to rush to meet the needs of the victims of Hurricane Maria.

- **Effective Practice: Mayor and FEMA Disability Integration Office working Together** - One participant said the mayor of her town was able to provide assistance to a family of a boy whose condition depended on having powered medical equipment 24 hours a day. She expressed appreciation for the municipality and the mayor who responded to the call. She agreed that each municipality should establish a program or a record of persons who are bedridden and have disabilities.
- **Effective Practice: Formation of the Puerto Rico Disability Relief Network** - Out of the tragedy, a coalition of organizations has formed, The Puerto Rico Disability Relief Network, to help ensure appropriate treatment of populations with disabilities across Puerto Rico.

C. Sheltering

- **The Government Needs to Improve Management of Shelters and Provide Training of staff** - A community member said there were significant concerns with shelters in Puerto Rico. There were people with no experience running or working at shelters.
- **The Government Should Ensure Shelters Have Sign Language interpreters** - Several community members told us about challenges

with shelters during the hurricane. One community member told us that municipalities should have shelters for the deaf community including people who know how to work with persons who are deaf. Interpreters must be at each shelter. There were deaf persons in a shelter where no one could communicate with them for two or three weeks.

- **The Government Needs to Ensure that Shelters Are Prepared to Serve People with Disabilities and Access and Functional Needs.** There were concerns about people who had conditions like asthma and that bathrooms were not open all the time, which can greatly impact people with disabilities.
- **The Government Should Ensure that Shelters Accommodate the Needs of the Elderly** - A community member said it is important to be mindful of the needs of seniors such as by placing them close to the bathrooms.
- **The Government Should Support Independent Centers that Provide Shelter for the Community** - A participant said that her organization sheltered persons who were elderly, persons with disabilities, and persons who were bedridden and alone. They took in around 400 people. However, the Department of the Family did not provide support.

D. Access to FEMA Resources and Programs

- **FEMA Disability Integration Personnel are Willing to Go to Areas Not Previously Visited** - One participant said that FEMA personnel from disability integration came into the municipality asking for a census of persons with access and functional needs and that they that they did this work to find the families and reported 140 homes but never received a response from FEMA personnel. He provided his name and contact information to FEMA for follow-up and FEMA Disability Integration personnel encouraged others to contact FEMA with identified needs.
- **The FEMA Disability Integration Advisor Partnered with Local Organizations to Support the Deaf Community** - One community organization said it was especially difficult for the deaf community members who didn't have any means of transportation. With the support of FEMA's Disability Integration Advisor, the organization was able to support members of the deaf community, worked with the

municipality to provide transportation, and provide food and supplies. The organization provided the list of deaf people to community leaders so that they would be able to help them in the future.

- **FEMA Should be Consistent in its Provision of Sign Language Interpreters** - One participant noted that a deaf person obtained the support of a local organization to contact FEMA and communicate through an interpreters. FEMA told him he needed to get an interpreter and when FEMA visited him, they didn't bring an interpreter. This was addressed and on the second appointment, FEMA provided an interpreter.
- **FEMA Should Have a Greater Role in Providing Generators to Persons with Disabilities who are in Need** - One community member urged FEMA to provide more support for access to generators.
- **FEMA Should Develop Options for Providing Access to FEMA Information/Benefit Applications in Case Power is Down** - Because of lack of communication, people wanted to access FEMA websites to ask for help but obviously they didn't have the access so there must be alternative ways to access the information.

E. Services and Supports for Recovery

- **Non-profits and Service Providers Should Continue to Have a Role in Recovery Efforts** - One organization mentioned that it has worked since the day after the disaster to spread out help to help people with all types of disabilities. The organization is still working diligently in recovery.
- **The Government Should include Faith-based Groups in Recovery Efforts** - Municipalities should include faith-based groups in recovery efforts. One organization, which consisted of 53 churches, took part in food distribution as well as in the recovery effort. The organization urged all municipalities to take a census of persons in the community and to include churches in the recovery phase.
- **The Puerto Rico Central Government Should Support Meeting the Needs of People with Disabilities in Recovery** - After the discussion of

the role of FEMA and municipalities, one participant said there is also a need to have the support of the state government. FEMA stepped in to give Puerto Rico support and individual assistance; however, the government of Puerto Rico's role is also important.

- **The Government Should Use Recovery Funds to Support People with Disabilities** - One participant said Puerto Rico is receiving millions of federal dollars for recovery and that there is a need to use the funds to focus on the needs of persons who have disabilities and access and functional needs. Other states after experiencing hurricanes provided a wide range of services for people with disabilities, including employment services. This is also important for Puerto Rico.
- **The Government Should Comprehensively Address the Mental Health Needs of the Population in Recovery Efforts** - There is a need to address mental health issues during the recovery phase. One participant said "every Puerto Rican, each and every one of us suffered because of hurricane Maria. We suffered and are still suffering." He said it was now necessary to help those who need it the most, referring to populations who have mental health conditions.
 - **Effective practice:** Among other efforts there was a campaign for the public on accessing to medical services and psychiatric services all around the island.
 - **Effective practice:** Once the power was back up a web page was set up that contained all the resources in the community and where the needs were.

III. **Recovery Presentation**

FEMA personnel provided a presentation on recovery sector-based efforts so that the disability community could understand these efforts and get involved.

IV. **Conclusion**

Officer Quinn thanked the community members and organizations that took the time to participate in the listening session and to share their comments and concerns.