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Committee on Homeland Security  
Subcommittee on Emergency Preparedness, Response and Recovery**

Hearing on:

**“PROTECTING EVERY CITIZEN:  
ASSESSING EMERGENCY PREPAREDNESS FOR UNDERSERVED POPULATIONS”**

Tuesday, July 23, 2019

10AM

Saint Peter’s University

47 Glenwood Avenue

Jersey City, New Jersey

**Statement for the Record**

**Marcie Roth, CEO**

The Partnership for Inclusive Disaster Strategies, Inc.

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The Partnership for Inclusive Disaster Strategies, Inc. is a nonprofit, nonpartisan, disability inclusive emergency and disaster organization established in Charleston, SC, in 2016. The Partnership for Inclusive Disaster Strategies does not currently receive any federal funding.

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# **“PROTECTING EVERY CITIZEN: ASSESSING EMERGENCY PREPAREDNESS FOR UNDERSERVED POPULATIONS”**

*By Marcie Roth, CEO, Partnership for Inclusive Disaster Strategies, Inc.*

## Statement

Good Morning Chairman Payne and distinguished Committee Members. I am honored to appear before you today.

My name is Marcie Roth and I am the CEO of the Partnership for Inclusive Disaster Strategies, a membership organization founded by Portlight Inclusive Disaster Strategies in 2016.

I am here today to report that, despite an investment of over [34 billion dollars in emergency preparedness funding in the past 15 years](#), our communities remain unprepared for disasters, and the people most disproportionately impacted are people with disabilities, older adults and others with access and functional needs. I am able to report this with authority, because this has been my entire focus for the past 19 years, both inside FEMA for almost 8 of those years.

In 2009, I was appointed by President Obama as Senior Advisor to the FEMA Administrator for Disability Issues. I was also named as the congressionally mandated Disability Coordinator, responsible for ensuring FEMA meets all of its disability related obligations established in the Post Katrina Emergency Management Act of 2006. And, I was also charged with establishing and directing FEMA’s Office of Disability Integration and Coordination from 2010 until my departure in 2017.

My disaster policy and operations responsibilities included:

- Advising Senior Leadership by leading agency and interagency development and implementation of disability inclusive emergency management policy and procedures throughout preparedness, response, recovery and mitigation, to ensure the federal government was meeting its obligations to provide equal access, nondiscrimination and reasonable accommodations and modifications for disaster impacted people with disabilities before, during and after disasters.
- Leading development and delivery of training and technical assistance tools provided by FEMA to first responders, emergency managers, and a wide array of stakeholders in states and communities across the country.
- Building a Disability Integration Cadre, one of FEMA’s 23 Disaster Response and Recovery Cadres.

In developing the Cadre, I was charged by the Administrator with hiring 285 disability experts, developing, implementing and serving as a qualification system official to ensure the level of expertise of Cadre members in the field.

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Between 2013 and 2017, the Cadre had over 400 disaster deployments, and I was personally deployed to catastrophic disasters as a Qualified Lead for over 500 days. Deployment teams included as many as 65 qualified specialists and trainees in larger disasters, with some serving as direct advisors to the Federal Coordinating Officer, and others working in the field alongside other FEMA employees to support implementation of FEMA's obligations to disaster impacted people with disabilities in federally declared disasters.

I assumed the position of CEO for the Partnership for Inclusive Disaster Strategies (the Partnership) in 2017. The Partnership is a coalition of local, national and global disability rights, emergency management, public health and community leaders committed to equal access and whole community inclusion before, during and after disasters. We are the only membership organization in the US with a sole focus on the needs and rights of disaster-impacted people with disabilities, older adults and people with access and functional needs. Our coalition focuses on the access and functional needs of countless people who are disproportionately impacted in disasters due to inadequate planning, preparedness and accessibility. This includes people who may require assistance, accommodation or modification due to any situation (temporary or permanent) that limits their ability to take action in an emergency.

In addition to people with disabilities, this includes people who are marginalized, stigmatized or excluded, older adults, individuals with limited language proficiency, low literacy, temporary and chronic health conditions, pregnant women and people experiencing homelessness, limited access to transportation or the financial resources to prepare for, respond to, and recover from a disaster.

Our US members lead disability rights initiatives in every congressional district and virtually every community across the country. Globally, we bring our expertise and leadership to disaster risk reduction, climate change adaptation, human rights, humanitarian action, strategic development, and resilient community initiatives.

The disproportionate impact of disasters on people with disabilities, older adults and others who also have access and functional needs is not insignificant. In fact, People with disabilities and older adults are two to four times more likely to die or be injured in a disaster. due to a lack of planning, accessibility and accommodation, most are not due to diagnostic labels or medical conditions.

According to the [Centers for Disease Control](#), one in four adults, 26% of the population has one or more disabilities. There are at least [seven million children with disabilities](#), 14% of all school age children as well, and [15% of the population is over age 65, and will grow to 1 in 5 people in the U.S over the next 10 years.](#)

Interruption of medical care and disability services were the primary cause of almost 3000 deaths following hurricane Maria. [Almost 15% were attributed to an inability to access needed](#)

[medications and almost 10% were caused by unmet needs for respiratory equipment requiring electricity.](#) Most of these individuals had disabilities related to chronic health conditions.

[71% of deaths in Hurricane Katrina were people over the age of 60. , 50% of the deaths in Super Storm Sandy and 77% of people who died in the California wildfires](#) were over 65 and many had disabilities.

[Over 2.5 million people use medical equipment and devices that require electricity.](#)

About 46 percent of the U.S. population used one or more prescription drugs in the past 30 days, according to a survey from the [National Center for Health Statistics](#). Without uninterrupted access in a disaster, many of these people will require a higher level of health care at the very time when access to healthcare will be at its most limited.

There are laws in place to ensure equal access, without exception, in a disaster. The Rehabilitation Act of 1973 protects the civil rights of persons with disabilities. It prohibits discrimination on the basis of disability by the federal government, federal contractors, and by recipients of federal financial assistance.

- Any recipient or sub-recipient of federal funds is required to make their programs accessible to individuals with disabilities. Its protections apply to ALL programs and businesses that receive ANY federal funds.
- This applies to all elements of physical/architectural, programmatic and effective communication accessibility in all services and activities conducted by or funded by the federal government.

Under the Rehabilitation Act, “entities selected to receive a grant, cooperative agreement, or other award of federal financial assistance from the U.S. Department of Homeland Security (DHS) or one of its Components, including State Administering Agencies must comply with civil rights obligations. Sub recipients have the same obligations as their primary recipient to comply with applicable civil rights requirements and should follow their primary recipient’s procedures regarding compliance with civil rights obligations.”<sup>12</sup>

Equal access to disaster services has been promised to children and adults with disabilities since passage of the Rehabilitation Act of 1973, 46 years ago. However, the promise remains unfulfilled. This is despite extensive legal protection; despite countless “lessons learned” documents, produced over fourteen years since the nation’s failed response to hurricane Katrina; and, despite claims that actionable emergency plans exist, children and adults with disabilities were consistently denied equal access to disaster-related programs and services throughout the

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<sup>1</sup> Department of Homeland Security. “Civil Rights Evaluation Tool, OMB Control No. 1601-0024.” <https://www.dhs.gov/sites/default/files/publications/dhs-civil-rights-evaluation-tool.pdf>.

<sup>2</sup> U.S. Department of Justice, “ADA Best Practices Tool Kit for State and Local Governments,” <https://www.ada.gov/pca toolkit/chap7emergencygmt.htm>.

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catastrophic disasters of 2017 and 2018 and are still being denied in 2019. These equal access failures extend to all aspects of disaster response and recovery including:

- Alerts, warnings and notification
- Actionable information and instructions
- Evacuation
- Sheltering in the most integrated setting
- Health maintenance and acute medical care
- life-saving and life-sustaining goods and services
- Food and potable water
- Registering for disaster services including FEMA and state/territory emergency programs
- Temporary and permanent housing
- Return to home, school, work and community life
- Disaster recovery and mitigation investments

In addition to the obligations that come with the expenditure of every federal dollar, before, during and after disasters, the Americans with Disabilities Act of 1990 prohibits recipients from discriminating on the basis of disability in the operation of public entities, public and private transportation systems, places of public accommodation, and certain testing entities.

In order to ensure compliance, recipients must provide program access, ensure effective communication, and provide physical access for persons with disabilities in developing budgets and in conducting programs and activities.

The US Supreme Court decided in its 1999 Olmstead decision that the Americans with Disabilities Act requires provision of services to individuals with disabilities in the “most integrated setting appropriate to the needs of the individual”.

In 2007, the US Department of Justice instructed state and local governments in their [ADA Best Practices Tool Kit for State and Local Governments, Chapter 7](#) that “The ADA requires people with disabilities to be accommodated in the most integrated setting appropriate to their needs, and the disability-related needs of people who are not medically fragile can typically be met in a mass care shelter. For this reason, people with disabilities should generally be housed with their families, friends, and neighbors in mass care shelters and not be diverted to special needs or medical shelters.” ... “Special needs and medical shelters are intended to house people who require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital.”

“The ADA requires emergency managers and shelter operators to accommodate people with disabilities in the most integrated setting appropriate to their needs, which is typically a mass care shelter” ... “Local governments and shelter operators may not make eligibility for mass care shelters dependent on a person’s ability to bring his or her own personal care attendant.”

Despite this, the use of “medical special needs shelters”, “medical friendly shelters”, “special needs shelters” “Federal Medical Stations” and other terms describe the only type of emergency sheltering provided for many individuals with disabilities living in the community and not appropriately served in a nursing home or hospital. The use of these facilities has been prevalent in many of the recent disasters requiring evacuation of disaster impacted communities.

These shelters have operated in Florida, Louisiana, South Carolina, North Carolina, Virginia and other states with federal disaster declarations over the past three years with people being sheltered in what is frequently described as circumstances that are “less than optimal”.

The use of any of these facilities to meet the disaster related sheltering needs of individuals with disabilities who “don’t require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital”<sup>3</sup> must be halted. Each of these facilities is a place of public accommodation and most receive some federal funds. Thus, these facilities must comply with Title II of the ADA and Section 504 of the Rehabilitation Act.

We have also seen the use of “evacuation centers”, including those funded with FEMA P-361 grant funds,<sup>4</sup> which, despite the grant instructions, are repeatedly described by local and state government as “different than shelters” and “not required to provide disability accommodations” such as accessible bathrooms, personal assistance, interpreters, cots and other reasonable accommodations.

Stakeholders report civil rights violations that were due to failure to provide necessary guidance, training and technical assistance to state and local government; failure to monitor compliance; and failure to enforce civil rights laws that apply before, during and after disasters.

Contributing to these failures is contradictory information about the requirements for sheltering people with disabilities in emergencies and disasters. Further confounding the problem with inconsistent civil rights guidance and lack of enforcement from the responsible federal agencies is a lack of clarity about which agency has ultimate responsibility for and ownership of the obligation for enforcing the requirement to provide sheltering to people with disabilities in the most integrated setting throughout emergencies and disasters.

### **HHS Office for Civil Rights (OCR)**

“Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts will help ensure that responsible officials are in compliance with Federal civil rights laws and that the disaster management in the affected areas by Hurricane Florence is successful”<sup>5</sup>

### **HHS Centers for Disease Control and Prevention (CDC)**

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<sup>3</sup> <https://www.ada.gov/pcatoolkit/chap7shelterprog.htm>

<sup>4</sup> <https://www.fema.gov/fema-p-361-safe-rooms-tornadoes-and-hurricanes-guidance-community-and-residential-safe-rooms>

<sup>5</sup> <https://www.hhs.gov/about/news/2018/09/13/ocr-issues-guidance-to-help-ensure-equal-access-to-emergency-services-medical-information-during-hurricane-florence.html>

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“Somewhere between a temporary shelter and temporary hospital, a Federal Medical Station is a non-emergency medical center set up during a natural disaster to care for displaced persons with special health needs—including those with chronic health conditions, limited mobility, or common mental health issues—that cannot be met in a shelter for the general population during an incident.”<sup>6</sup>

### **HHS Office of the Assistant Secretary for Preparedness and Response (ASPR)**

Federal Medical Stations “sustain from 50 to 250 stable primary or chronic care patients who require medical and nursing services.” Federal Medical Stations provide “low acuity care for patients with chronic illnesses whose access to care is impeded due to the disaster.”<sup>7</sup>

### **DOJ**

“Shelters are usually divided into two categories: (1) “mass care” shelters, which serve the general population, and (2) “special needs” or “medical” shelters, which provide a heightened level of medical care for people who are medically fragile. Special needs and medical shelters are intended to house people who require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital.”<sup>8</sup>

### **DHS Office for Civil Rights and Civil Liberties (CRCL)**

“Under federal civil rights laws, sheltering services and facilities must be accessible to children and adults with disabilities. Sheltering and temporary housing of persons with disabilities must take place in the most integrated setting appropriate to the needs of the person, which in most cases is the same setting people without disabilities enjoy. See, [Guidance on Planning for Integration of Functional Needs Support Services in General Population](#). The intent of this federal guidance is to ensure that individuals are provided appropriate accommodations and are not turned away or moved from general population shelters and temporary housing or inappropriately placed in other, more restrictive, environments (e.g., “special needs” shelters, institutions, nursing homes, and hotels and motels disconnected from other support services).”<sup>9</sup>

### **FEMA**

1. “Segregating children and adults with and without disabilities who have access or functional needs and those with whom they are associated from general population shelters to “special needs” shelters is ineffective in achieving equitable program access and violates Federal law. People with disabilities are entitled by law to equal opportunity to participate in programs, services, and activities in the most integrated setting appropriate to the needs of the individual. Additionally, children and adults with and without disabilities who have access and functional needs should not be sheltered separately from their families, friends, and/or

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<sup>6</sup> <https://www.cdc.gov/phpr/stockpile/fedmedstation.htm>

<sup>7</sup> <https://www.phe.gov/Preparedness/support/medicalassistance/Pages/default.aspx>

<sup>8</sup> <https://www.ada.gov/pcatoolkit/chap7shelterprog.htm>

<sup>9</sup> <https://www.dhs.gov/sites/default/files/publications/notice-nondiscrimination-during-disasters.pdf>

caregivers because services they require are not available to them in general population shelters.”<sup>10</sup>

2. “providers must be aware that they may fall into more than one category of provider. For example, a state agency that receives Federal financial assistance must comply with laws that apply to Federal financial assistance recipients as well as to laws that apply to state and local governments. Non-profit organizations that receive Federal financial assistance to provide food, clothing, shelter, or transportation in connection with an emergency must comply with obligations applicable to recipients of such assistance as well as requirements generally applicable to nonprofit organizations that provide services to the public.”<sup>11</sup>

Despite this, the US Department of Health and Human Services Centers for Medicare and Medicaid repeatedly issue waivers to states in “Public Health Emergency Declarations” which allow states to place individuals with disabilities directly into nursing homes from their own home or from hospital beds to make room for others who may need that bed, regardless of the needs of the individual for nursing home level care. This is in direct violation of the Americans with Disabilities Act and the Rehabilitation Act.

These waivers typically allow:

- waiver of the 3-day hospitalization requirement before eligibility for nursing home admission, because of “shelter needs” not the needs of the individual.
- permission to move acute care hospital patients to nursing homes based on the needs of other patients, not their own level of care needs
- placement of individuals who “need skilled nursing care as a result of the emergency”, without any defining criteria to protect the civil rights of eligible disaster impacted individuals with disabilities.

The Partnership filed a complaint with the Department of Justice, Department of Homeland Security, Department of Health and Human Services and FEMA in September 2018. We were granted a “listening session” in November of 2018. There has been no further action taken to address this conflicting guidance to states, and as recently as last week, another waiver was issued to Louisiana allowing nursing home placement of disaster impacted people.<sup>12</sup>

Regardless of the federal agency ultimately responsible for ensuring the rights of people with disabilities in disasters, at the heart of these violations of the rights of people with disabilities is a total failure on the part of FEMA to have its Congressionally mandated Disability Coordinator implementing her responsibilities as defined in the [Post Katrina Emergency Management Reform Act of 2006](#). . These responsibilities include:

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<sup>10</sup> [https://www.fema.gov/media-library-data/20130726-1831-25045-7316/fnss\\_guidance.pdf](https://www.fema.gov/media-library-data/20130726-1831-25045-7316/fnss_guidance.pdf)

<sup>11</sup> <https://www.fema.gov/media-library-data/20130726-1617-20490-6430/section689referenceguide.pdf>

<sup>12</sup> <https://www.hhs.gov/about/news/2019/07/12/azar-declares-public-health-emergency-louisiana-tropical-storm-barry.html>

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- ensuring that the needs of individuals with disabilities are being properly addressed in emergency preparedness and disaster relief
- consulting with organizations that represent the interests and rights of individuals with disabilities about the needs of individuals with disabilities in emergency planning requirements and relief efforts in the event of a natural disaster, act of terrorism, or other man-made disaster;
- ensuring the development of training materials and a curriculum for training of emergency response providers, State, local, and tribal government officials, and others on the needs of individuals with disabilities;
- ensuring the availability of accessible transportation options for individuals with disabilities in the event of an evacuation;
- ensure that the rights and wishes of individuals with disabilities regarding post evacuation residency and relocation are respected

The Partnership and our member organizations have continually attempted, since she first assumed her position in 2017 to consult with and collaborate with the FEMA Disability Coordinator, without success.

We are the nation's organizations that represent the interests and rights of individuals with disabilities about the needs of individuals with disabilities in emergency planning requirements and relief efforts in the event of a natural disaster, act of terrorism, or other man-made disaster. The Disability Coordinator has also stopped the FEMA Individual Assistance Directorate from collaborating with us, and it wasn't until Senator Casey reached out to FEMA that we were granted an invitation to meet with FEMA senior leadership. This meeting requested by one of our community leaders three months ago. has not yet been scheduled.

We have heard from many of the FEMA Disability Integration staff that they have been directed not to speak with us, and disability leaders in disaster impacted communities report a continual lack of local presence of FEMA qualified disability integration cadre representatives. We have also been told that the Cadre has been discontinued and most of the trained and qualified disability experts have left the agency. Over a year ago, we were told by the Disability Coordinator that FEMA would be hiring Disability Integration Specialists in every state and training the entire agency to ensure qualified disability integration experts would be ensuring the rights of disaster impacted people with disabilities would be protected by FEMA. However, it appears that only one Disability Coordinator has been hired in TX, existing training has been discontinued and a contract to develop new training has not yet been awarded. Further, at least one of the Regional Disability Specialist positions, Region IV, remains unfilled after an 18-month vacancy- a region that has sustained repeated disasters over the past 2 years.

In its May 24, 2019 report to President Trump, [Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters](#) the National Council on Disability made the following recommendations:

- ♣ The Department of Justice (DOJ), the Department of Health and Human Services (HHS), the Department of Homeland Security (DHS), and the Department of Housing and Urban Development (HUD) monitor and enforce the Americans with Disabilities Act (ADA) Olmstead integration mandate and the Rehabilitation Act obligation to use federal funds in such a way that people are served in the most integrated setting appropriate to their needs.
- ♣ All relevant federal agencies engage with national, state, and local coalitions of disability led organizations and stakeholders.
- ♣ DOJ assesses the equal access and non-discrimination civil rights compliance performance of the American Red Cross and other shelter and mass-care providers in relation to actions resulting in institutionalization of disaster survivors with disabilities.
- ♣ The Federal Emergency Management Agency (FEMA) explore ways to expeditiously modify its Individual Assistance registration process to curtail the incidence of institutionalization of individuals with disabilities.
- ♣ DHS/FEMA and HHS/Administration for Community Living (ACL) provide grant funds to support Independent Living Centers in supporting disaster-impacted people with disabilities in their community. (This funding should incorporate all five core services of Independent Living Centers, including their obligation to prevent and divert institutionalization of disaster-impacted people throughout disaster response and recovery.)
- ♣ Relevant federal agencies integrate disaster-related services for veterans with disabilities with all other emergency and disaster services in order to address the current gap in coordination.
- ♣ Legislation be introduced and swiftly enacted to address all gaps in meeting the civil rights obligations to people with disabilities impacted by disasters.

In June 2019, the Government Accountability Office (GAO) released a report entitled, *FEMA Action Needed to Better Support Individuals Who are Older or Have Disabilities*.

The GAO report was requested by a bipartisan and bicameral group of seventeen Congressional committee leaders to evaluate FEMA's disaster assistance for older Americans and individuals with disabilities.

The findings detail what the Partnership has attempted to address with FEMA since hurricane Harvey made landfall in August 2017. Among these are FEMA's system-wide failure to ensure disaster-impacted people with disabilities and older adults are provided with equal access to FEMA assistance programs and critical needs services, such as food, water, and healthcare in the 2017 hurricanes.

The GAO findings also evaluate the 2018 restructuring of the FEMA Office of Disability Integration and Coordination (ODIC), which further dismantled critical supports to disaster-impacted people with access and functional needs, and the communities and responders serving them, without developing, implementing, or communicating a replacement plan.

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The GAO report provides recommended actions and an agreed timeline, stretching over a year into 2020, for FEMA to implement.

However, these plans are hollow due to the continued silence towards disability community leaders and key stakeholders from FEMA's Office of Disability Integration and Coordination, the Individual Assistance Division, and FEMA's Administrator.

Immediately after the GAO report was released, two bipartisan, bicameral bills were introduced by Senator Robert Casey, Senator Susan Collins, Congressman James Langevin, Congressman Chris Smith, Congresswoman Donna Shalala and Congresswoman Jenniffer Gonzalez-Colon to address the urgent need to protect every citizen by meeting the federal government's obligations to underserved and multiply marginalized people with disabilities, older adults and people who also have access and functional needs.

The Real Emergency Access for Aging and Disability Inclusion for Disasters Act (REAADI) [S-1755](#) and [HR-3208](#) and the Disaster Relief Medicaid Act (DRMA) [S-1754](#) and [HR-3215](#) will work together to provide solutions that help individuals maintain their health, safety and independence before, during, and after disasters by:

- Funding research;
- Developing and delivering technical assistance and training;
- Creating a national commission with people with disabilities, older adults, experts on disability inclusive emergency management and government and community stakeholders to provide guidance on disability and aging issues before, during and after disasters;
- Providing uninterrupted access to Medicaid services when recipients must evacuate across state lines;
- Department of Justice review of ADA non-compliance settlement agreements in preparedness, response and recovery efforts;
- Government Accountability review of federal funds expended in disasters to ensure compliance with Rehabilitation Act requirements.

We call on Congress to quickly enact these bills into law before the next disaster strikes.

Despite years of planning, people with disabilities and older adults continue to pay the price for our collective emergency planning shortfalls. Many are still without the basic necessities to meet their independence, safety and health maintenance needs. Many more have been denied their basic right to equal access to federally funded emergency programs and services.

The people most knowledgeable about the needs of the people in their own community are expected to volunteer their time, while government and the disaster business giants get grants,

donations and tax payer dollars to perpetuate strategies long proven to be bad for individuals and just as bad for communities.

The time to monitor and enforce the laws is overdue and effective practices for whole community inclusion must be led by experts in disability and aging inclusive emergency management.

It's time to stop admiring the problems. It's just not an option to fail again. The Partnership for Inclusive Disaster Strategies remains fully committed to working collaboratively with FEMA, DHS, HHS and our government to ensure that the rights and disaster-related needs of the 61 million Americans with disabilities, over 50 million older adults, and countless others who also have access and functional needs are no longer denied. Until we all join forces and work together - led by those of us with lived experience - our families, neighbors, and communities remain in harm's way as soon as the next flood, fire, tornado, hurricane, earthquake, terrorist attack, or other disaster strikes.

The Partnership and our allies from across the country are looking to Congress for your leadership and appreciate the opportunity to speak with you today.