



3075 Adeline Street • Suite 155 • Berkeley CA 94703-2577 • (510) 225-6400 • <http://www.wid.org>

Marcie Roth
Executive Director and Chief Executive Director
World Institute on Disability

STATEMENT FOR THE RECORD

Submitted to the House Transportation and Infrastructure Committee
Subcommittee on Economic Development, Public Buildings, and Emergency Management

“Experiences of Vulnerable Populations During Disaster”

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The World Institute on Disability (WID) is a global nonprofit 501(c)3 organization established in 1983 and continually led by people with disabilities. WID works to advance the rights and opportunities of over 1 billion people with disabilities worldwide, bringing policy into action and operationalizing inclusion.

Good morning Chairman Titus, Ranking Member Katko, and distinguished members of the Committee. It is an honor to testify before you today, as one voice among the 26 percent of the US population who have disabilities.

I am the Executive Director and Chief Executive Officer for the World Institute on Disability, one of the first global disability rights organizations, founded in 1983 by people with disabilities and continually led by disabled people for the past 37 years. Thank you for allowing me to share the experiences of people with disabilities during disasters, the topic of today's hearing.

I have been active in the disability rights movement since I was in high school and have worked as an advocate for the rights and services needed by people with disabilities throughout my 45-year career. Along the way, I acquired my disability, raised two disabled children, married a man with a disability and, though some don't own it, most of my family and friends have disabilities, too.

Disability Rights, Disasters and Public Health Emergencies

Since the Centers for Disease Control and Prevention (CDC) reported in 2018 that at least 1 in 4 adults has a disability, it's safe to assume that many people listening to or reading my testimony has a disability too. Like me, they have sweeping civil rights protections against discrimination on the basis of their disability and are entitled to equal access throughout almost all aspects of daily life in the US.

Two days ago, July 26, 2020, the 30th anniversary of the Americans with Disabilities Act was celebrated. This law, known as the ADA, gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. The ADA also assures equal opportunity for individuals with disabilities for access to businesses, employment, transportation, state and local government programs and services, and telecommunications. These rights are never suspended or waived, including before, during and after public health emergencies and disasters.

In the words of one of the original authors of the ADA, Bob Burgdorf, written in the Washington Post "The ADA was a response to an appalling problem: widespread, systemic, inhumane discrimination against people with disabilities. In 1971, a New York judge described people with disabilities as "the most discriminated [against] minority in our nation."

My laser focus on emergency preparedness and improving disaster outcomes for people with disabilities and building accessible disaster-resilient communities began in the immediate aftermath of the September 11, 2001 terrorist attacks, when I was asked to advise the White House on the rights and urgent needs of thousands of people with disabilities living in the area around ground zero.

Appointed by President Obama to the U.S Department of Homeland Security - Federal Emergency Management Agency from 2009 to 2017, I served as Senior Advisor to Administrator Fugate, establishing and directing the FEMA Office of Disability Integration and Coordination. I also served as FEMA's Congressionally mandated Disability Coordinator; a

requirement established when the Post Katrina Emergency Management Reform Act (PKEMRA) amended the Stafford Act in 2006.

Now I'm going to speak about what happens to people with disabilities in disasters, again and again. The news is not good.

Having a disability does not make people more vulnerable in disasters. Everyone is potentially vulnerable to the impacts of disasters. What makes people vulnerable is the failure communities and governments to plan for the inclusion of people with disabilities in every aspect of the disaster cycle, including community preparedness and disaster exercises, accessible alerts and warnings, building and community evacuation, sheltering and temporary housing, access to health maintenance and medical services, and all aspects of the recovery process.

Failure to comply with the ADA and other key civil rights laws is what makes people with disabilities more vulnerable in disasters and public health emergencies. Most notable among the civil rights laws is the Rehabilitation Act of 1973 which requires equal physical access, program access and equally effective communication access. The Rehabilitation Act, now almost 50 years old, applies to EVERY federal dollar spent, including all funds expended by the federal government before, during and after disasters, and every federal dollar spent by grantees and sub grantees, including states, tribes, territories and their subgrantees from cities and counties and any other user of federal funds.

The US Department of Justice, FEMA, the Departments of Health and Human Services, Homeland Security, Housing and Urban Development have all confirmed that they know that these civil rights laws are NEVER waived or suspended, including in a disaster. Even when waivers of other laws are granted in a federally declared disaster, those waivers never apply to the ADA and the Rehabilitation Act, nor do they apply to the non-discrimination requirements in the Stafford Act.

Despite this, the Centers for Medicare and Medicaid have repeatedly issued waivers in public health emergencies that allow states to bypass many of the protections that keep people with disabilities out of institutions, nursing homes and other congregate facilities, in direct violation of their rights. These Section 1135 of the Social Security Act blanket waivers have been issued repeatedly over the past four years with dire consequences for people with disabilities, despite their ADA, Stafford and Rehabilitation Act rights.

I have repeatedly raised these concerns for years, including in a formal complaint from the Partnership for Inclusive Disaster Strategies in 2017, filed with the Departments of Justice, Health and Human Services, Homeland Security and FEMA. As the Executive Director of the Partnership for Inclusive Disaster Strategies, I was granted a "listening session" hosted by the Disability Rights Section of the Department of Justice in November 2017. Representatives from HHS and DHS attended, FEMA RSVPed to DOJ that they would attend, but never showed up. In my one-way conversation, while everyone "listened", I requested that these federal representatives exercise their obligation to enforce disability rights laws since the civil rights of people with disabilities are never allowed to be waived or suspended. I never heard another word about my complaint and the issuance of 1135 blanket waivers continued in many subsequent disasters, including the current COVID-19 pandemic.

The National Council on Disability (NCD) is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. In May 2019, NCD published [*Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters*](#). In NCD's cover letter to President Trump, Presidential Appointee NCD Chairperson Neil Romano tells the president, "NCD has found that people with disabilities are frequently institutionalized during and after disasters. The report examines factors that lead to institutionalization. Then, most critically, it provides recommendations to eliminate institutionalization of people with disabilities during and after disasters. It also recommends how to improve community readiness to meet obligations that require equal access to emergency and disaster services and programs in the most integrated setting appropriate for disaster-impacted people." Chairman Romano tells President Trump, "There will be no remedy in future disasters without sweeping changes."

Where do we need to focus?

After many years of calls for action to address the disaster rights and needs of 26% of the population, we have largely failed. Among the many issues we are asking this Committee to prioritize, include the following:

- Focus on disability inclusive preparedness, response and recovery.
 - Please help us find out who is monitoring and enforcing FEMA and HHS' use of disaster funds to ensure that every federal dollar spent or granted to others to spend are in full compliance with all of the obligations under the Rehabilitation Act of 1973? We can't seem to get that answer and can't seem to get an answer for who is responsible for monitoring and enforcing the agencies required to monitor and enforce the expenditure of billions- perhaps trillions of taxpayer dollars!
 - Are we centering our efforts on the disaster needs of multiply marginalized Black, Indigenous, Brown and other People of Color?
 - Are the rights and needs of disabled prisoners and detainees prioritized in emergency and disaster planning?
 - What efforts are being taken to ensure people with intellectual disabilities, autistic people, people with mental health needs and other disabled people who are most often the most excluded from emergency planning?
 - Why are funds being directed to improve nursing homes when they very obviously are incapable of protecting the people in their facilities from infections, including deadly COVID-19. Invest funds in home and community based services and accessible housing!
 - Who is responsible for monitoring the GAO findings regarding FEMA's obligations to people with disabilities? Despite several recent reports about the failures of the Office of Disability Integration and Coordination, several agreements remain unfulfilled and although GAO reported that they weren't conducting a civil rights review, many disability civil rights violations have been

documented and remain unresolved. If GAO is not responsible for addressing these documented civil rights violations, who is?

- Are people with disabilities involved in planning, participating in and reviewing disaster exercises?
- Do they get alerts and warnings in formats accessible to them? Has the Integrated Public Alerts and Warning Act adequately addressed all accessibility requirements? Information must be accessible to be actionable.
- The only service provided to individuals under the nationwide COVID-19 disaster declarations is “Crisis Counseling”. Currently, FEMA has been unable to provide any information about which states are providing accessible crisis counseling services or what those accommodations are and how to locate them.
- Can they evacuate from multistory buildings? Can they evacuate the community with everyone else, even if they need accessible transportation, or are they left behind?
- Are shelters prepared to meet their access and functional needs?
- Will service animals be welcomed? Despite relentless efforts, people with service animals are still repeatedly denied access to shelters.
- Can people with disabilities register for FEMA assistance? Can they request reasonable accommodations for the application process when they apply? After years of repeatedly raising these issues, FEMA told GAO over a year ago that they would have this resolved. It still is not, and we are told, “hopefully by the end of 2020”.
- Will national disability organizations finally be invited to work with FEMA’s Office of Disability Integration and Coordination after being refused time and again since 2017.
- How will personal assistance and other accommodations be provided in concurrent disasters during the pandemic? There is a need for immediate solutions to prevent admissions to nursing homes and other COVID-19 infested congregate facilities.
- There is a national shortage of accessible and affordable housing before disasters destroy homes. This must be a priority or the cascade that leads to institutionalization won’t be stemmed.
- Likewise, we must prioritize Home and Community Based Services funding and Money Follows the Person funding to prevent institutionalization and provide the resources for nursing home transition and other deinstitutionalization for all who wish to live in the community, without exception.
- Meeting the educational needs of students with disabilities remains an especially urgent need during the pandemic. The disaster related needs of students with disabilities have been an issue in every recent disaster, and this must be addressed so that planning can prevent the disproportionate interruption of the educational needs of these students, in violation of their rights under the Individuals with Disabilities Education Act.

- And, disaster recovery and mitigation must always start with a commitment to universal design standards and accessibility as imperatives. Without accessibility, community resilience is impossible.
- Immediately pass the bi-partisan, bi-cameral Real Emergency Access for Aging and Disability Inclusion for Disasters (READI for Disasters Act)- [S-1755](#) and [HR-3208](#) and Disaster Relief Medicaid Act (DRMA) [S-1754](#) and [HR-3215](#). These bills will go a long way towards closing many of the deadly gaps in disasters and public health emergencies, not just for people with disabilities, but for the whole community.

The current crisis

On March 3, 2020, in anticipation of what was to come, disability advocates led by the [Partnership for Inclusive Disaster Strategies](#), the [National Council on Independent Living Emergency Preparedness Subcommittee](#), and my organization, the [World Institute on Disability](#) issued a [National Call to Action](#) joined by [194 other local, national, and international groups](#).

The coalition, led by the Partnership followed our Call to Action with a [letter to Vice President Pence and the White House COVID-19 Task Force](#) on March 9, 2020.

It took many complaints before CMS amended their [COVID-19 1135 blanket waiver guidance last month](#), adding one line to the document originally published 4 months earlier. The added language reads, “States are still subject to obligations under the integration mandate of the Americans with Disabilities Act, to avoid subjecting persons with disabilities to unjustified institutionalization or segregation.

In a footnote, CMS also added “Please note that consistent with the integration mandate of Title II of the ADA and the Olmstead vs LC decision, States are obligated to offer/ provide discharge planning and/or case management/ transition services, as appropriate, to individuals who are removed from their Medicaid home and community based services under these authorities during the course of the public health emergency as well as to individuals with disabilities who may require these services in order to avoid unjustified institutionalization or segregation. Transition services/ case management and/or discharge planning would be provided to facilitate these individuals in their return to the community when their condition and public health circumstances permit.” Based on reports, this has not stemmed the placement of people with disabilities in COVID infested nursing homes.

Who is affected?

On March 13, 2020, President Trump declared the COVID-19 pandemic a national emergency. While 8 percent of the country’s COVID-19 cases have occurred in long-term care facilities, deaths related to Covid-19 in these facilities account for 50 percent of the country’s pandemic fatalities, according to Larry Kudlow, representing President Trump on CNN’s State of the Union on 7/26.

According to Mr. Kudlow’s numbers, in the 137 days that have followed President Trump’s National Emergency Declaration, 50% of the 150,000 US COVID-19 deaths, 75,000 , were

almost all people with disabilities who despite their right to live in the community, died a horrific death, without any loved ones by their side, in congregate facilities, such as nursing homes, long term care facilities, and group homes. Countless other disabled people are also dying from COVID in juvenile and adult psychiatric hospitals and carceral facilities, such as jails, prisons and detention centers. Many of these people are multiply marginalized Black, Indigenous, Brown and other people of color, most of them were poor.

According to a New York Times database, as of July 23, the virus has infected more than 335,000 people at some 15,000 facilities. These numbers would indicate that there are still well over a million institutionalized people who could still be prevented from contracting the virus. Clearly, given the abject failure of these facilities to protect the people under their care, this won't be possible in those 15,000 facilities.

Disability rights advocates from across the country are calling for immediate relocation of all disabled people currently in congregate facilities. Many of the nation's 400+ Centers for Independent Living, non-residential community advocacy organizations, serving most communities in every state, have completed thousands of successful transitions from nursing homes to non-congregate community living. They are ready, willing and able to implement their federally mandated nursing home transition services. In a July 6, 2020 [letter to the nation's governors](#), these community living experts and their allies notified the governors that they will assist state and federal government authorities to meet their civil rights obligations under the ADA and the Rehabilitation Act by rapidly relocating nursing home residents with disabilities to far safer transitional housing where they would continue to receive all of the supports and services they require in the privacy and safety of non-congregate community locations. FEMA has been repeatedly requested to provide guidance to governors about how to use the current disaster declarations to enable the use of Public Assistance, Category B funds, Emergency Protective Measures, to fund the emergency protective needs of hundreds of thousands of people with disabilities in dangerous COVID infested congregate facilities. FEMA has shown no urgency in providing this life saving guidance. People with disabilities living in our communities, in their own homes, have a radically lower infection rate than people living in congregate settings. Home and community-based services are also a very cost-effective solution.

In the NCD report [*Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters*](#)

“data shows it is more cost-effective to provide community-based services like accessible shelters versus institutionalization. In NCD's 2009 report *The Cost of Deinstitutionalization: Comparing the Cost of Institution Versus Community-Based Services*, the average annual expenditure for a state institution was \$188,318 compared to \$42,486 for Medicaid funded home and community-based services.¹ The fiscal disparity between the two options is staggering and further supports NCD's recommendations in this report that institutionalization of persons with disabilities during and after disasters is not an economically sound option.”

Real Experiences

Here are the experiences of three disabled people affected in extreme ways in the midst of the COVID-19 federally declared disaster.

Katy is a disability advocate in Yuba City, CA. She lives in her own home, and, as a person with quadriplegia, she receives In-Home Supportive Services (IHSS) as an alternative to out-of-home care. This State of CA program is described as “enabling recipients to remain safely in their own homes”. Due to COVID, Katy’s in-home support providers stopped coming and, despite repeated promises from the state, she was told IHSS workers were unavailable. Without in-home support, Katy’s health and safety were in danger. She could find people to hire on Craigs List, but they were far more expensive than the \$133/day IHSS currently pays but IHSS won’t cover the additional cost. Instead, Katy was forced to go into a nursing home at a cost to the state of \$600/day, a \$467 more expensive option in an especially dangerous place for anyone to be forced to live.

Kristen is a mother of four, from Atlanta. During childbirth, she had a massive stroke, resulting in paralysis and a brain injury. After a recent hospitalization related to her brain injury, the hospital was in a hurry to discharge Kristen so they could fill her bed with a higher paying patient. While she and her friends scrambled to find an accessible home for her and her children to live, she was relocated 300 miles away to a nursing home in TN against her will. As a result of that decision, she can’t see her children and she has been told that since she is out of state, proceedings to sever her parental rights will begin soon.

Both Katy and Kristen have submitted Civil Rights complaints to the US Department of Health and Human Services Office for Civil Rights. As of this hearing, neither has had any action taken by HHS.

Last month, a Black, disabled, 46-year-old African American father of five was one of the tens of thousands of disabled people who had contracted COVID-19 in a nursing home. However, Michael Hickson, who was paralyzed after a massive heart attack caused a brain injury in 2017, did not die from the virus. He was euthanized, despite his wife’s pleading with doctors to provide life sustaining care to her husband. In the words of one reporter, Michael “was black and paralyzed, so doctors decided his life wasn’t worth saving”.

Michael’s wife, Melissa, legally recorded an exchange she had with her husband’s doctor about Michael’s care. “[As the recording shows](#), they agreed that Michael should not be intubated, but Melissa still wanted Michael to be treated aggressively. The doctor insisted aggressive treatment wouldn’t “help him improve” and “right now, his quality of life . . . he doesn’t have much of one.” “What do you mean?” Melissa asked. “Because he’s paralyzed with a brain injury, he doesn’t have quality of life?” “Correct,” the doctor flatly replied. “The doctor admitted he’d had “three patients survive who were in Michael’s situation” but claimed “Michael’s “quality of life is different from theirs.” The others “were walking and talking people. I don’t mean to be frank or abrasive, but at this point, we are going to do what we feel is best for him along with the state, and this is what we decided.” Michael, a father of 5, was denied food and water and he died a horrific death six days later, with none of his loved ones by his side.

Kristen is a black woman and Michael was a black man.

Advocates had to move quickly earlier in the declared disaster to prevent children and adults from rationing of their medical care and medical devices based simply on their disability and the perceived quality of life.

“[The Center for Public Representation](#) and others [filed complaints](#) alleging that crisis standard of care plans in two of the states currently being hardest hit by COVID-19, Arizona and Texas, discriminate against people with disabilities, older adults, and people of color, placing these communities at risk of substantial and imminent harm—and the real risk of being denied basic and emergency treatment—during the pandemic.

In response to the disability community’s strong advocacy, the U.S. Department of Health and Human Services’ Office of Civil Rights (HHS OCR) published a [bulletin](#) on March 28, 2020 to ensure that covered entities follow civil rights laws, including Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which “prohibit discrimination on the basis of disability in HHS funded health programs or activities.” The guidance explains that entities funded by HHS cannot deny people with disabilities medical care “on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities.” It also discusses the obligations of hospitals to ensure equal access and effective communication.”

In many states, efforts have been taken to provide immunity to all hospitals, nursing homes and other congregate facilities, protecting those facilities and their employees from any criminal or civil liability for their treatment decisions and actions. Families, disability advocates and advocates for older adults are outraged. [One advocate in New York told the New York Times](#) “Having liability can cause a facility to be more diligent and prevent incidents occurring that will cost them money,” said Susan M. Dooha, the executive director of the Center for Independence of the Disabled. “The preventive power of liability has been muted.”

Based on the findings of the report, [Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters](#) NCD recommends that:

- ♣ 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.

Recommendations from the [Emergency Relocation of Congregate Setting Residents](#) letter to the National Governors Association:

- Relocate residents to safe, non-congregate, cohort settings that house no more than one person per room
- Identify residents who want to transition to Home & Community Based Services (HCBS)
- Require that institutions / long-term care facilities grant access to essential CIL staff and transition coordinators in order to implement these relocation plans
- Expedite HCBS eligibility determinations for those who want to remain in the community OR who refuse to return to an unsafe congregate setting
- Work with your Department of Commissioners, etc. to utilize alternative funds (such as FEMA Public Assistance Category B funds) to cover the costs of care, shelter and food during disaster relocations
- Immediately lift the restrictions on visitations. Data shows visits from family are critical to the well-being and quality of life of people housed in these congregate settings. Not allowing visitations is contributing to the increases in death

And, the Partnership for inclusive Disaster Strategies led our COVID-19 Coalition to issue the following [Legislative Recommendations for Public Health Emergencies and Disasters](#)
To meet the urgent and immediate needs of people with disabilities, including multiply-marginalized people, throughout the COVID-19 Public Health Emergency, Presidential Disaster Declarations, concurrent disasters and in preparation for future disasters and public health emergencies

- There must be the establishment and funding of one or more Disability, Emergency and Disaster Technical Assistance Centers led and managed by disability inclusive emergency management experts, operational within 30 days of enactment in order to meet the immediate lifesaving and life sustaining needs and protecting the rights of 61 million adults with disabilities and for others who also have access and functional needs in a disaster or public health emergency
- Purposes of the Disability, Emergency and Disaster Technical Assistance Centers: `
- Operating a National Disability Disaster and COVID-19 rights and needs Hotline
 - Developing and delivering remote just-in-time training on the COVID-19 rights and needs of people with disabilities, with a specific focus on:
 - The rights and immediate needs of people with disabilities who need supports and services to protect themselves from exposure.
 - People with disabilities who are in quarantine.

- People with disabilities who are in isolation or in an acute care medical setting.
- Information for medical, public health, and public safety officials, government and non-government, and private sector entities to understand their obligations to people with disabilities, before, during and after public health emergencies and disasters.
- Meeting continuity of operations and continuity of services for serving people with disabilities across the lifecycle and throughout the disaster cycle.
- Public engagement, coordination between all public and NGO stakeholders to provide accessible information, promising and good practices, and problem-solving via disability accessible teleconference and web-based information sharing.
- Crisis counseling and Disaster Case Management for people with disabilities, eligible as a result of Federal Disaster Declarations. Crisis counseling and Disaster Case Management must be provided by disability culturally competent providers, and must be equally effective for all people with communication disabilities. Crisis Counseling and Disaster Case Management must be provided without interruption and gaps. Auxiliary aids and services to make communication equally effective include sign language interpreters, real-time captions, CART, plain language, easy read, Braille, large print, screen reader and other alternative formats. Alternative and augmentative communication is used by many people with disabilities to meet their daily communication needs. For people with COVID-19 whose ability to communicate may be temporarily affected, equal access to crisis counseling can be provided by utilizing auxiliary aids and services to meet their urgent crisis communication needs.
- Amendment to Stafford Act - Use of Disaster Response and Recovery Funds
- Fund certain “nonprofit entities” in Category B language - amended to define funding for a training & technical assistance center.
- Funding for disability-led organizations providing life saving and life sustaining assistance in a federally declared, Stafford Act eligible disaster or emergency.
- Fund state, local, tribal and territorial government entities to track the displacement of people with disabilities into skilled nursing facilities (SNF) and other institutions with or without the use of a CMS 1135 Blanket Waiver.
- Require and fund federal, state, local, tribal, and territorial government entities to ensure disability services and supports are provided in the most integrated settings appropriate to the person.
- If the person is in an acute care setting, all reasonable accessibility accommodations and modifications of policies and practices are provided without interruption.
- To maintain all reasonable accessibility accommodations and modifications of policies and practices are provided without interruption at home and throughout transition home from an acute care or institutional setting.
- Increase Home and Community Based Services (HCBS) funding
- Expand funding for Money Follows the Person (MFP)
- Fund federal entities to monitor recipients and subrecipients of federal funds to ensure compliance throughout all disaster-related placement decisions by recipients and subrecipients of federal financial funds within 30 days, and with quarterly reports to Congress.

Additional recommendations for legislative action are all drawn from the 5/24/19 report from the National Council on Disability report to President Trump:

Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters

- Require CMS to establish a process for Medicaid portability and continuity of services within states and among states, tribes and territories during disasters and public health emergencies to ensure uninterrupted health maintenance and medical care in the least restrictive environment for Medicaid recipients.
- Require that all recipients and subrecipients of federal funds receive just-in-time training in the scope of their obligations to people with disabilities. This training must be developed and delivered by disability led organizations with knowledge, skills and abilities. This training must include information advising that federal funds may be revoked due to noncompliance with the obligation to receive services in the most integrated setting appropriate and that this obligation applies during disasters.
- Training on the scope of the obligations of recipients and subrecipients of federal financial assistance to people with disabilities during the period of hospitalization and discharge for individuals impacted by public health emergencies and disasters, including those who have been abandoned during evacuation, sheltering, and transition to long-term housing.
- Funding will be provided to disability-led organizations to deliver technical assistance to local, state, tribal, territorial and federal agencies responsible for emergency preparedness, community resilience, and disaster-related services, programs, supports, or activities to engage with national, state, and local coalitions of disability-led organizations and stakeholders.
- Fund NCD to lead a review of the National Response Framework, Emergency Support Function Annexes, and Federal Interagency Operations Plans and all other applicable federal doctrine to determine any required updates to specifically address responsibility for meeting the equal access, health maintenance, safety, and independence needs of children and adults with disabilities to prevent institutionalization.
- Fund an organization with expertise in IDEA, ADA, Rehab Act and Stafford Act to assess and make recommendations that disaster-impacted students with disabilities are not excluded from distance learning and returning to school with their peers and that all supports and services included on their IEP or Section 504 plan are provided without interruption. This includes providing services during school closure and upon school reopening in order to meet their individualized educational needs and to prevent institutionalization.
- Fund a comprehensive assessment of with recommendations for the establishment and execution of a seamless and integrated process in Emergency Support Functions #6 and #8 to prioritize health maintenance for children and adults with disabilities and seamlessly deliver services and supports to people in the most integrated setting throughout the evacuation, sheltering, hospitalization, temporary housing, and disaster recovery. Recommendations must include actionable steps for the HHS Secretary's Operations Center and the FEMA Emergency Support Function Leadership Group to

ensure the rights and needs of people with disabilities are maintained throughout the period of a declared public health emergency and disaster.

- Establish a roster of federal agencies who must provide senior leadership participation and active engagement in a community led public private partnership with disability organizations with specific expertise and involvement in national disability inclusive emergency management policy and practice.
- Authorize and appropriate funds for DHS and FEMA to provide disaster preparedness grants specifically targeted to organizations led by and serving marginalized communities, including but not limited to people with disabilities experiencing poverty; people with disabilities experiencing homelessness; women with disabilities; people of color with disabilities; and members of the LGBTQ community with disabilities.
- Provide funding and quarterly reporting by DOJ, DHS and HHS to monitor and enforce the obligation under both the ADA and the Rehabilitation Act to serve people with disabilities in the most integrated setting appropriate to their needs.
- Fund the FCC to reestablish its Emergency Access Advisory Committee to establish effective communication access requirements for alerts, warnings and notification, including provision of American Sign Language and other existing and new assistive technology. These guidelines should be developed in consultation and collaboration with DOJ, applying the requirements for equal effective communication access. Implementation should include monitoring and enforcement by the FCC and DOJ.
- Fund immediate operations and research into solutions for existing disability service providers (such as independent living centers, paratransit service providers, meals on wheels, medical supply providers, developmental disability service providers, personal assistants, direct support professionals, birth to 3, ADRCs, AAA, sign language interpreters, peer support, respite, etc to jointly plan for, share information and meet the emergency and disaster needs of the people one or more of them maintain in their database.
- Fund research on HIPAA and Privacy Act laws to determine if and how they need to be revised to allow providers to share information and resources in emergencies and disasters. This is an alternative to the use of “special” registries that repeatedly fail to provide a solution for meeting the civil rights obligations the government has to people with disabilities in emergencies and disasters.
- Fund NCD to review the Federal Mass Evacuation Plan, DRRA and PKEMRA evacuation planning requirements, and any other plans that use federal funding for evacuation be reviewed by the Department of Justice, Department of Transportation, Department of Homeland Security, and other federal agencies with a role in planning, implementing and/or funding evacuation initiatives to ensure compliance with disability civil rights obligations throughout disaster response and implement all necessary corrective action immediately.
- Fund HHS CMS to develop and implement within 30 days, a comprehensive federal database in collaboration with all other federal entities with admission and monitoring or funding and reimbursement obligations to ensure that all admissions to hospitals and long-term care facilities during and after disasters are monitored at every admission and discharge and that people placed are provided with the assistance needed to return to their community with all supports and services they need to regain and maintain their independence. Reporting to congress must begin NLT 60 days and must continue

quarterly until all admissions from the start of a declared emergency (including public health emergency) and disaster have returned home (or died).

- Fund DOJ and other federal entities with enforcement authority to monitor and prohibit the automatic placement of individuals with disabilities in hospital and nursing home settings and direct state and local entities to immediately provide supports and services in the most integrated setting appropriate to any person who does not need this level of care. Monitor and enforce civil rights compliance with Titles II and III of the ADA regarding sheltering.
- Fund DOJ, DHS, and HUD to monitor and enforce compliance with obligations for emergency sheltering in a disaster consistent with emergency sheltering requirements under the Fair Housing Amendments Act. Compliance should occur in transient and long-term emergency shelters.
- Congress funds all elements of the READI and DRMA Acts not otherwise specified in these recommendations to ensure that the rights of people with disabilities are protected and that the needs of people with disabilities and older adults are met in concurrent and future disasters.
- This includes:
 - Establish a National Research Center to conduct research and collect and analyze data to determine recommended practices for including people with disabilities and older adults in planning during and following disasters. Establish a “projects of national significance” program to increase the involvement of people with disabilities and older adults in the planning and response to disasters.
 - Establish a National Commission on Disability Rights, Aging and Disasters that will provide recommendations on how to ensure effective emergency preparedness, disaster response, recovery, and community resilience efforts for people with disabilities and older adults.
 - Establish one national and 10 regional Training and Technical Assistance Disability and Disaster Centers that provide comprehensive training, technical assistance, development of funding sources, and support to state, tribal, and local disaster relief; public health entities; social service agencies; and stakeholder groups.
 - Require and fund DOJ to create an oversight committee that will review all ADA settlement continued agreements related to disaster-response activities for the years 2005 to 2017.

Medicaid Relief for Disaster Survivors

- Amending the Social Security Act to provide medical assistance available to relief-eligible survivors of disasters during relief coverage periods in accordance with section 1947.
- Disaster Relief Medicaid for Survivors of Major Disasters.
- Promoting Effective and Innovative State Responses to Increased Demand for Medical Assistance Following a Disaster.
- HCBS Emergency Response Corps Grant Program.
- Targeted Medicaid Relief for Direct Impact Areas.
- Presumptive and Continuous Eligibility, No Documentation Required.
 - Fund DOJ to provide pointed guidance to sister federal agencies to address the issue of outdated regulations that conflict with the Olmstead integration mandate.

- Fund the University of Minnesota Institute on Community Integration University Center on Excellence in Disabilities Residential Information Systems Project (RISP) to expand their research on institutionalization during and after disasters in all states and territories to include people with all types of disabilities.
- Fund DOJ to assess 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 and issue orders for immediate corrective actions as needed.
- Fund DOJ to issue a fact sheet that defines monitoring and enforcement obligations in order to ensure compliance with civil rights requirements in the placement, as well as to track and use of federal funds associated with emergency and disaster sheltering of people with disabilities.
- Fund Independent Living Centers and other affordable and accessible housing experts to provide individual and household disaster case management focused on the transition and permanent housing needs of disaster-impacted people with disabilities.
- Fund Independent Living Centers and other experts on affordable and accessible housing to provide individual and household disaster case management focused on the transition and permanent housing needs of disaster-impacted people with disabilities during concurrent and future disasters.
- Fund HUD to establish metrics and measure the nationwide availability of the ready supply of accessible, adaptable, affordable, and disaster-resistant permanent and temporary housing.
- Fund FEMA and HUD to create systems for collecting and publishing all disaster recovery and mitigation expenditures for housing that is subject to compliance with requirements under the Rehabilitation Act, Fair Housing Amendments Act, and the ADA. This reporting systems must measure and report compliance with accessibility standards.
- Fund DOJ to monitor and enforce civil rights compliance throughout all phases of disaster response to: a. Prevent abandonment on the part of government entities, such as National Guard and other recipients and subrecipients of federal financial assistance. b. Ensure compliance throughout all disaster related placement decisions made by recipients and subrecipients of federal financial assistance. c. Ensure compliance with Titles II and III of the ADA pertaining to sheltering.
- Fund FEMA to explore ways to modify their Individual Assistance registration process expeditiously to curtail the incidence of institutionalization of individuals with disabilities during concurrent and future disasters.
- Fund the DHS Office for Civil Rights and Civil Liberties to lead and manage the 25-plus federal agencies included in Executive Order 13347, which established the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC), to collaborate to ensure moving forward that emergency preparedness plans incorporate the perspectives and needs of individuals with disabilities, and that barriers to access, services, and planning are removed.
- Fund member agencies of the ICC to place disability experts from their agency into the field during federally declared disasters in all FEMA Joint Field Offices and Area Field Offices throughout disaster operations. These experts must be qualified by either the FEMA Qualification System or the National Qualification System to ensure adequate

expertise in guiding compliance with the civil rights of disaster-impacted people with disabilities to prevent institutionalization during concurrent and future disasters.

- Fund HHS to establish a process for states and territories to immediately loan and replace durable medical equipment, consumable medical supplies, assistive technology, and disability services and supports, well as disaster case management to disaster survivors with disabilities, in order to provide equal access and non-discrimination throughout emergency response to meet immediate health, safety, and independence needs.
- Fund the Veterans Administration and HHS to ensure disaster-related services for veterans are integrated with all other emergency and disaster services to address the current gap in coordination between services for veterans with disabilities and services for other people with disabilities.
- Fund the immediate provision of experts on reasonable accommodations for every disaster applicant until such time as applicants with disabilities can request and receive these reasonable accommodations through the FEMA application.

In Closing

One of my favorite sayings is associated with the Chinese symbols for Crisis, Danger and Opportunity. "Crisis is an opportunity riding on a dangerous wind."

In these very troubled times, we all face three choices. Do we go back to what wasn't working before? Do we stay stuck right where we are until the next catastrophic event forces us to scramble again, or do we use this unprecedented opportunity to boldly move forward on the dangerous wind that is blowing, all of us, to create and sustain a resilient country that prioritizes the resilience of the people who will once again be disproportionately impacted if we don't act. I choose the bold commitment to resilience for all and I ask you to join me in turning words into action.

Thank you for listening.