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**STATEMENT FOR THE RECORD**

**Submitted to the House Homeland Security Committee  
Subcommittee on Emergency Preparedness, Response and Recovery**

**Supporting Underserved Communities in Emergency Management**

**July 19, 2022**

marcie roth Page 2 7/18/22 Good morning, Chairman Demings, Ranking Member Cammack, and distinguished members of the Subcommittee on Emergency Preparedness, Response and Recovery. It is an honor to testify before you today, as one voice among the 26 percent of the US population, one in 4 adults, who have disabilities and who are continually underserved and left behind before, during and after disasters.

I am the Executive Director and Chief Executive Officer of 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 almost 40 years.

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 needs of 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, became the proud grandmother of an amazing 3-year-old with a disability and, though some don't own it, most of my family and friends have disabilities, too.

My laser focus on emergency preparedness, 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 New Yorkers 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.

I am here today because, despite my very best efforts, my work and the work of many others has failed to improve disaster outcomes for people with disabilities. This is especially and disproportionately true for disabled multiply marginalized Black, Brown, Indigenous and other People of Color, LGBTQIA+, and other intersecting identities.

In fact, I am horrified to have to testify that I think people with disabilities are in even greater peril today than when I last testified before this committee in 2019.

However, after spending nearly 8 years in a leadership position at FEMA, and many more years providing guidance, tools, training, and technical assistance to local, state, national, tribal, territorial, federal and international emergency management stakeholders, I am confident that emergency management can center the needs and rights of the people and communities most disproportionately affected by disasters and by doing so, improve disaster resilience for the whole community.

In one week, on July 26, 2022, the 32<sup>nd</sup> anniversary of the Americans with Disabilities Act will be 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 1971, a New York judge described people with disabilities as “the most discriminated [against] minority in our nation.” 2 years later, the Rehabilitation Act of 1973 which requires equal physical access, program access and equally effective communication access was passed. Almost 50 years old, this law 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.

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.

However, it wasn’t until passage of the Post Katrina Emergency Management Reform Act (PKEMRA) in 2006 that non-discrimination on the basis of disability was added to the Stafford Act.

Even today, FEMA frequently cites “Federally Supported, State Managed, Locally Executed” as an excuse for failures in serving people with disabilities in violation of civil rights laws. While this may be an acceptable excuse when it doesn’t involve federal funds, FEMA’s obligations (and the obligations of all funders of federal financial assistance) to comply and to ensure their grantees and subgrantees comply remain solidly in place, without exception

### **Equality in access and equity in outcomes.**

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 of communities and governments to plan for the equal access and equitable outcomes for 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.

Both equality and equity are important but are not interchangeable. Equity means fairness, and that everyone gets what they need. While we are reaching and striving for equity, it is not an alternative to equality. Equal access is one imperative aspect of

achieving and maintaining equity. Equal access for people with disabilities is a legal, civil rights obligation, never waived or diminished in a disaster. Incrementalism is not an acceptable or permissible alternative to complying fully with the law. The government's commitment to equity is laudable, and necessary, but no one is "off the hook" when it comes to equal access to programs, services, places, or information for people with disabilities, before, during or after a disaster.

One of the most egregious failures of the federal government is failing to monitor and enforce equal access obligations that cannot, must not be ignored when spending or granting tax dollars to others to spend. The most egregious failure is continuing to look the other way, shrugging shoulders, or letting years of inaction pass with when these violations are brought to the attention of officials who have the responsibility to act.

### **Underserved AND underheard**

When I was at FEMA, Administrator Fugate made it very clear to me right from the start of my appointment and throughout my almost 8 years as his senior advisor that my top priority was disability community engagement. This included meeting regularly with national, state, and local disability leaders, sending dozens of disability advisors into disaster impacted communities during FEMA response to federally declared disasters, developing and delivering training and technical assistance to support emergency managers and stakeholders on how to meet the access and functional needs of the whole community, inclusive of, but not limited to people with disabilities.

Since 2017, FEMA leadership has actively and systematically dismantled most community engagement mechanisms, significantly decreased the disability expert workforce, shut down existing training and failed to provide any new training.

### **In a 2017 Government Accountability Office report, Federal Disaster Assistance: FEMA's Progress in Aiding Individuals with Disabilities Could Be Further Enhanced**

GAO found that "ODIC also has not established goals for how many state and local emergency managers should take its key training on integrating the needs of individuals with disabilities into disaster planning. Nor has ODIC evaluated alternative methods to deliver the training more broadly, such as virtually in addition to classroom training. ***As a result, state and local emergency managers may be ill-prepared to provide effective disaster services to those with disabilities.***"

5 years later, one recommendation from that report is marked "closed- implemented" and the other two remain "open".

Among the 1000+ courses available through the FEMA Emergency Management Institute and funded by tax dollars, there are currently two courses that mention disability. One, IS: 368 referred to in the report as "closed-implemented", is a short video developed in 2014 and never updated, and the other, IS: 1019, is specifically focused on disaster recovery "codes and standards".

In 2019, after a bipartisan request from co-chairs of every relevant House and Senate committee, including the House Committee on Homeland Security. another GAO report was published **“Disaster Assistance: FEMA Action Needed to Better Support Individuals Who Are Older or Have Disabilities”** This report included seven new recommendations. Of those, 5 of the recommendations are noted as “closed-implemented” however, one is a timeline to offer training to FEMA’s partners. Another that is still open is that “The FEMA Administrator should develop a plan for delivering training to FEMA staff that promotes competency in disability awareness. The plan should include milestones and performance measures and outline how performance will be monitored.”

In another “closed-implemented” recommendation to update "Integrating Access and Functional Needs into Emergency Planning" it is noted that ODIC officials “expect to field the course starting in August 2020”. As of July 2022, this course, has been unavailable for 5 years, surely contributing to underserving disaster-impacted people with disabilities and other marginalized people.

At the same time, the frequency, intensity, and duration of disasters of all kinds is growing exponentially. The disproportionate impact on people with disabilities and other marginalized people is exacerbated by the failures of the federal government to implement, monitor and enforce the laws that protect the people most likely to be harmed. Basic access to power, potable water, heating and cooling is taken for granted by most people, yet these are among the most deadly effects of climate driven disasters, along with fires and floods.

During this period, our nation has experienced 84 separate billion dollar weather and climate related disasters, many other disasters costing less than one billion dollars, other federally declared disasters unrelated to weather, and, of course COVID disasters and public health emergencies, both in place since early 2020. This includes all 50 states, the District of Columbia, 5 territories and 32 tribes.

The US Departments of Justice, Health and Human Services, Homeland Security, Housing and Urban Development and FEMA have all confirmed that disability 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 several 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 in 2017, filed with the Departments of Justice, Health and Human Services, Homeland Security and FEMA. 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, beginning in January 2020 and reissued by HHS Secretary Becerra four days ago on July 15, 2022.

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, former Presidential Appointee NCD Chairperson Neil Romano told the president, “NCD has found that people with disabilities are frequently institutionalized during and after disasters. The report examined factors that led to institutionalization. Then, most critically, it provided recommendations to eliminate institutionalization of people with disabilities during and after disasters. It also recommended 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 told President Trump, “There will be no remedy in future disasters without sweeping changes.”

On March 3, 2020, in anticipation of what disability leaders feared 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 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](#), 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.” This did not stem the placement of people with disabilities in COVID infested nursing homes.

Advocates also had to move quickly to prevent children and adults from having their medical care and medical devices rationed based simply on their disability and the perceived quality of their life. Both implicit and explicit biases were further threatening the lives of people with disabilities.

“[The Center for Public Representation](#) and others [filed complaints](#) alleging that crisis standard of care plans in two of the states 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 discussed 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.”

For two years, countless people have been institutionalized in understaffed, under resourced COVID infested congregate facilities, with waivers in place that have resulted in continual denial of basic human rights, huge data gaps and even bigger loss of life. On April 22, 2022, CMS updated their use of blanket waivers in place for over 2 years. Absent from their update was elimination of nursing home admission flexibilities, to

meet the needs of providers, NOT people being admitted without civil rights and life safety protections in place.

### **Collaboration and Partnership**

The World Institute on Disability believes collaboration and partnership between disability-led organizations like ours and government and non-government organizations must be among our highest priorities. Through our work with the Partnership for Inclusive Disaster Strategies, we have been closely collaborating, coming together each and every day, at 6pm ET since February 28, 2020 with a laser focus on addressing the urgent needs of people with disabilities throughout the COVID-19 public health emergency and concurrent disasters, including those driven by the impact, duration, and intensity of climate change.

We are joined almost every day by representatives from the US Department of Health and Human Services (HHS) Centers for Disease Control and Prevention (CDC), the American Red Cross, emergency managers and disability community leaders from across the country. The US Department of Homeland Security (DHS) Office for Civil Rights and Civil Liberties (CRCL) and the HHS Administration for Community Living (ACL) join at least weekly.

Despite extending continual invitations from the Partnership for Inclusive Disaster Strategies, the FEMA Office of Disability Integration and Coordination (ODIC) and the FEMA Office of Equal Rights (OER) rarely join us or participate in any of the Partnership's other invitations to collaborate. (Over the past 2 months, the ODIC Acting Director has begun to attend some meetings, however he rarely shares any information and has been unable to answer our questions.)

This is our ONLY shared communication since a large group of disability-led organizations and our allies met with FEMA Administrator, Deanne Criswell almost one year ago in August 2021 to share our urgent concerns about the needs of disaster-impacted people with disabilities. At that meeting, Administrator Criswell assured us that FEMA's Disability Coordinator and both ODIC and OER would follow up and work more collaboratively moving forward. This statutory obligation is included in the Post Katrina Emergency Management Reform Act (PKEMRA) mandate for the Disability Coordinator to *"consult 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"* among other statutory obligations. Despite Administrator Criswell's assurances, our contact from ODIC has only been in the form of announcements from the office and the last correspondence of any kind was in November 2021. While we were included in the audience for the FEMA Equal Rights Summit in November 2021, we've had no follow-up communication from OER, no summary, findings, transcript, or other output from that meeting.



To summarize, there has been no collaboration, no coordination, no dialogue, and no effort to seek community engagement or consult with a broad array of disability-led organizations.

Since November, COVID has raged, with Omicron causing devastating impact that has disproportionately affected people with disabilities of all ages. Recently, the Kaiser Family Foundation reported what we already knew, that as of 1/30/22, there have been [over 200,000 deaths in nursing homes](#), with countless disabled people of all ages dying in other long term care, carceral, psychiatric and other facilities.

*According to the Kaiser Family Foundation, “This death count is based on state and federal data sources. For the period between March 2020 and June 2021, the total number of deaths is based on state-reported data on LTCFs, including nursing homes, assisted living, and group homes, that summed to 187,000 resident and staff deaths. For the subsequent period between July 2021 and January 2022, we incorporated data reported to the federal government by nursing facilities (excluding other types of LTCFs), adding another 14,000 resident and staff deaths to the total. The total number of resident and staff deaths from these two sources, roughly 201,000, is likely an undercount of the true number of resident and staff deaths in LTCFs since it excludes deaths in long-term care settings other than nursing homes after June 30<sup>th</sup>, 2021. Additionally, not all states reported data on all types of LTCFs prior to June 2021.”*

And from the [Covid Tracking Project at the Atlantic](#): *Using state and federal data, we can estimate that as of March 2021:*

***About 8% of people who live in US long-term-care facilities have died of COVID-19—nearly 1 in 12. For nursing homes alone, the figure is nearly 1 in 10.***

***The most complete figures we can assemble are both an estimate and a severe undercount of the true impact on long-term-care residents. Because of the historical deaths missing from both state and federal data, non-standard state reporting, and the absence of federal reporting requirements for long-term-care facilities, we believe that the true toll of the pandemic among these residents is higher than these figures can show. [Read our analysis](#) or [use our data](#).***

*Throughout the pandemic, long-term-care facility deaths made up over a third of all US deaths based on COVID Tracking Project (CTP) data, which includes nursing homes, assisted living and other long-term care facilities. The Center for Medicare & Medicaid Services (CMS) only reports data for nursing homes, where a quarter of deaths in the US occurred. The impact on these communities is likely higher than this figure shows because of missing historical deaths from both state and CMS data, and inconsistent, non-standardized reporting by states.*

You may not think FEMA has a primary role in preventing the death of hundreds of thousands of disabled people in nursing homes and countless others denied personal assistance and personal protective equipment in the community. However, disability

leaders have been trying to work together with FEMA leaders on lifesaving and life sustaining efforts related to the pandemic since the very first days after COVID was declared a national disaster on March 13, 2020. We focused very specifically on the dire circumstances in congregate settings and the opportunity to relocate people with disabilities to non-congregate settings as an emergency protective measure, already covered under FEMA Public Assistance, Category B (Cat B). We knew Cat B was being used to relocate unhoused people and that [Centers for Independent Living](#) (CILs) are congressionally mandated to transition people with disabilities out of these settings, and also divert others from admission as one of their core services. This was an opportunity to work together to save hundreds of thousands of lives. CILs understood they would have to fund relocation costs and wait for reimbursement from their state. Some attempted to get their county and state to work with them. So far, only one county and one state has worked with one CIL; Roads to Freedom Center for Independent Living of North Central PA, to save one person through emergency relocation utilizing Cat B Emergency Protective Measures.

Many other disabled people have died as their CIL attempted to navigate across their county, state, and FEMA to help them put needed Memoranda of Agreements in place. They were repeatedly told that FEMA wouldn't allow this use of Public Assistance reimbursement.

Guidance from FEMA has not been forthcoming, and even now, after Roads to Freedom received reimbursement for lifesaving emergency relocation, FEMA has not accepted our invitations to work together to help more states to save disabled lives. There has been no guidance offered by FEMA to optimize the equitable use of Cat B to improve disaster outcomes for people with disabilities or to enforce the requirements that come with use of federal funds by FEMA's grantees and subgrantees in compliance with their civil rights obligations.

*KFF noted that "COVID-19 deaths in LTCFs make up at least 23% of all COVID-19 deaths in the US". Further, "nursing homes have continued to experience disproportionately high [case and death rates](#) in the country during the recent surge. Higher case rates may be attributed to the highly transmissible nature of Omicron and the nature of congregate care settings."*

There have been at least 20,000 COVID deaths in nursing homes since Administrator Criswell was appointed. Many of these deaths occurred after Roads to Freedom successfully navigated emergency relocation for which FEMA has subsequently reimbursed relocation costs to the state of PA, who subsequently reimbursed Roads to Freedom.

According to the [American Association of Retired People](#), "rates of COVID-19 cases and deaths in nursing homes rose in June for the second month in a row, ending several months of decline from the peak of the initial Omicron wave in January 2022.

- The rate of resident cases increased by 27% in the four weeks ending 6/19/22, compared to the previous four weeks. About 1 out of every 35 nursing home residents tested positive for COVID-19 in this four-week period.
- The rate of staff cases increased by 42% compared to the previous four weeks. About 1 staff member tested positive for COVID-19 for every 28 residents.
- More than one-third of nursing homes had a resident case during the four weeks ending 6/19/22, and two-thirds of facilities had a confirmed staff case.
- The rate of resident deaths increased by 54% compared to the previous month. About 1 out of every 1500 residents died from COVID-19 in the last month.”

How many of these deaths could have been prevented? How many more can we prevent, starting today, if FEMA were to prioritize the use of emergency protective measures for assisting people with disabilities to relocate out of congregate facilities and divert others from being admitted with the help of experts from CILs?

The World Institute on Disability (WID), The Partnership for Inclusive Disaster Strategies, and our allies from across the country would like to rebuild what was once a collaborative relationship with FEMA. We want to work with FEMA Headquarters and in the Regions in a shared effort to close systematic gaps that prevent FEMA from meeting its commitment to *“integrate equity as a foundation of its culture”* and fully accomplish its mission to help ALL people, before, during and after disasters, including disabled people.

We shared our stakeholder perspective on our top 10 FEMA priorities for 2022 earlier this year:

1. Talk directly and regularly with disability-led organizations who work on disability inclusive emergency management. We expect to be at the table and not the door. Bring in a mediator if necessary.
2. Work with us to save disabled lives now. It’s too late for hundreds of thousands of people with disabilities who could have been prevented from dying from COVID, but it’s not too late for people, including multiply marginalized people with disabilities, who could be assisted by the network of disability-led organizations across the country who want to work with FEMA.
3. Co-Host a summit with national disability-led organizations on Disability, Equity, Rights, Compliance, and the equitable use of Disaster Funds to jointly focus on improving the equitable use of federal disaster resources
4. Provide Guidance to SLTTs on:
  1. FEMA Personal Assistance Services Addendum
  2. Recent Disaster Assistance Application changes
  3. Transparent reporting on all Rehabilitation Act monitoring, compliance, and enforcement in all funds granted to states from FEMA.
  4. Utilizing Disability-led organizations as a primary source of qualified, culturally appropriate Disaster Case Management.

5. Engaging disability-led organizations throughout the development, control, play and review of exercises at all levels.
5. Recognize CILs and other community-based disability organizations as eligible Private Non-Profits in the next update of the Public Assistance Program and Policy Guide. (Pages 45-47).
6. Provide monthly reports on the long-delayed revision of E/L 197 and other relevant training issues highlighted in the February 2017 GAO report on training with emphasis on meeting disability rights obligations and achieving disability equity.
7. Convene a workgroup including disability-led organizations to identify and address gaps between Emergency Support Functions 6 and 8.
8. Meet with disability-led organizations working on the midpoint review of the United Nations Sendai Framework for Disaster Risk Reduction 2015-2030.
9. Co-Host a summit with national disability-led organizations on implementing a realistic Personal Assistance Services plan and performable contracts for federal as well as SLTT.
10. Co-Host a summit with national disability-led organizations on implementation and improvement of the Integrated Public Alerts and Warnings System to meet the notification requirements for equally effective communication access for people with disabilities in disaster

### **Priorities for Congress:**

Among the many issues we are asking this Committee to prioritize, please include the following:

- Focus on ***disability inclusive*** preparedness, response, and recovery centering the people and communities most disproportionately underserved and left behind.
  - 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? LGBTQIA+ people?
  - Are the rights and needs of disabled prisoners and detainees in carceral facilities prioritized in emergency and disaster planning?
  - What efforts are being taken to ensure the inclusion of people with intellectual disabilities, autistic people, people with mental health needs, people under guardianship 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.
- 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 and emotional support animals be welcomed? Despite relentless efforts, people with service animals are still repeatedly denied access to shelters.
- Has there been any guidance provided for assisting people with disabilities who request reasonable accommodations for the application process when they apply?
- 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 can provision of personal assistance and other accommodations be improved? There is still 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 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.

- 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)-and Disaster Relief Medicaid Act (DRMA). 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.

Based on the findings of the 2019 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, DRRRA 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.

### **One last thing...**

Our federal complaint process does not work in disasters. Waiting until there is measurable harm to an eligible complainant before the complaint can be acted upon probably doesn't work well under any circumstances. It most definitely doesn't work in a disaster. We must have a process for immediate action when a rights violation is about to occur. This includes failing to provide accessible alerts and warnings, accessible building evacuation and transportation, shelters without accessible bathrooms and showers, lack of access to resources to maintain health, safety and independence, turning service animals and emotional support animals away from shelters, failing to keep people in the most integrated setting appropriate to their needs, failing to provide equally effective communication access, plain language, reasonable modifications, meet specific dietary needs, separating families and natural supports, forcing people into medical settings to access electricity and so many other rights violations. If we had a way to intervene before the harm occurred, lives would be saved, disaster outcomes would improve and the whole community would benefit.

### **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 “build 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 build FORWARD, riding the fierce wind that is blowing, all of us, to create and sustain a resilient country that prioritizes equity and equality for the people who will once again be left behind if we don’t act.

I choose the bold commitment to equity, resilience, and justice for all and I ask you to join me in turning words into action.

Thank you for listening.