**STATEMENT FOR THE RECORD**

**3075**

 **Adeline Street #**

**155**

**Berkeley, CA 94703**

**T: 510.225.6400**

**www.wid.org**

**Marcie Roth**

**Executive Director and Chief Executive Director**

**World Institute on Disability**

**Submitted to the House Transportation and Infrastructure Committee**

**Subcommittee on Economic Development, Public Buildings, and Emergency Management**

***FEMA’s Priorities for 2022: Stakeholder Perspectives*”.**

February 14, 2022

Dear Chairman Titus, Ranking Member Webster, and distinguished members of the Committee.

Please accept written testimony from the World Institute on Disability and our partners from The Partnership for Inclusive Disaster Strategies.

The World Institute on Disability (WID) was founded in 1983. WID was the world’s first public policy center controlled by people with disabilities, dedicated to the promotion of independence and full inclusion in society of people with disabilities, committed to public education and converting policy into action.

WID’s global mission is to continually advance the rights and opportunities of over one billion people with disabilities.

We do this through our core services:

* Accessibility and Universal Design Solutions
* Emergency Preparedness, Disaster Risk Reduction and Climate Resilience
* Policies, Tools and Services for Global Community Living

WID 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 (over 715 days) 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.

A large group of disability-led organizations and our allies met with FEMA Administrator, Deanne Criswell in August 2021 to share our urgent concerns about the needs of disaster-impacted people with disabilities. 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,](https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/) 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 30th, 2021. Additionally, not all states reported data on all types of LTCFs prior to June 2021.”*

You may not think FEMA has a primary role in preventing the death of hundreds of thousands of disabled people in nursing homes. 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 people experiencing homelessness and that [Centers for Independent Living](https://acl.gov/programs/aging-and-disability-networks/centers-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 was not 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*](https://www.kff.org/coronavirus-covid-19/issue-brief/key-questions-about-nursing-home-cases-deaths-and-vaccinations-as-omicron-spreads-in-the-united-states/) *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.”*

As reported above, there have been at least 14,000 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. 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 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.

Our stakeholder perspective on our top 10 FEMA priorities for 2022:

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 no later than March 15, 2022, in preparation for the Global Platform for Disaster Risk Reduction in May 2022.
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