



To the National Council on Disability:

On behalf of the Consortium for Constituents with Disabilities Emergency Management Task Force, we submit these comments in response to National Council on Disability's (NCD) Request for Information on the creation of a State, Local, Territory, and Tribal (SLTT) Emergency Management Toolkit.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. The Emergency Management Task Force advocates for the rights of persons with disabilities as it relates to policies and services before, during, and after disasters to ensure everyone has access to needed supports and services.

As the nation's leading experts on Disability Inclusive Emergency Management, We respectfully suggest that, NCD should issue a broader call to action for the disability and disaster technical assistance and research centers identified in the Real Emergency Access for Aging and Disability Inclusion (READI) for Disasters Act, which NCD has supported in the past. Any effective strategy should prioritize what keeps people out of institutions and able to stay home, return home and to their community, and return to work and everyday life. We also urge NCD to build from recommendations from its 2019 report, *Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters*, and to support the creation of local pathways for what NCD has already recommended to Congress and President Trump.

From our perspective, current efforts highlight an important concern: until we have a solid foundation, we cannot build the structure, and without a structure, a toolkit would hold tools that are not designed for the job at hand. A toolkit by itself is not a strong solution without technical assistance and training. As NCD has already reported, the lack of training and technical assistance, combined with inadequate enforcement of the right to be served in the most integrated setting, has led to egregious practices that have caused short- and long-term institutionalization, and worse. As NCD reported in 2019, this is far more expensive than supporting individuals in their homes and communities. NCD wrote: "Once disaster survivors are institutionalized, it is difficult for



them to return to the community,” and also documented that community-based services are more cost-effective than institutionalization.

Further, the failure to prioritize these recommendations from 2019, and the failure to utilize FEMA Public Assistance Category B for life-saving and life-sustaining supports and services, where authorized under the Stafford Act, had a direct correlation to the deaths of hundreds of thousands of people with disabilities in congregate facilities over the next few years, due to COVID-19, public health emergency waivers, and the unprecedented transfers of disabled people of all ages out of acute care facilities and into long-term facilities. This practice brought people with COVID into facilities that had inadequate infection control measures to protect residents and brought people without COVID into facilities ridden with COVID. This is one of the greatest and most obvious failures of our national emergency management system, and it clearly shows that leaving solutions to local governments without training and technical assistance is a recipe for tragic outcomes and preventable death.

One Center for Independent Living (CIL), Roads to Freedom, was able to navigate “emergency relocation” utilizing FEMA Category B Emergency Protective Measures reimbursement funding as a lifesaving alternative. Without providing local CILs and other local independent living service providers with the funds, training, and technical assistance to keep people out of congregate facilities, and to drive and support local solutions, a generic toolkit will be nothing more than another well-intended but inadequate resource.

Disaster-related funding must also be flexible enough to meet real-life local conditions. Even where funds are made available, overly narrow grant terms or reimbursement instructions can prevent organizations from using those resources to address the actual life-saving and life-sustaining needs present in their communities. NCD should recommend a clear process for grantees to work with grant managers to make timely, reasonable adjustments based on local conditions, while maintaining accountability and fidelity to the purpose of the funds.

Whether the federal government is supporting SLTTs with Stafford Act and other Health and Human Services (HHS) public health emergency funds, or the entire responsibility falls to SLTTs, the need remains the same: research, training, and technical assistance resources, coupled with local support to disability-led organizations, are the most essential tools in every toolkit to improve outcomes for the whole disaster-impacted community.



A toolkit will not be enough to address all of the necessary components without expertise, resources, research, monitoring, and continual improvement. **These components include:**

- Prevention
- Disaster risk reduction
- Preparedness, including table-top and full-scale exercises
- Early warnings and accessible, actionable alerts
- Optimizing access
- Exercises and accessible emergency technology (geolocation, two way comms, mesh connectivity, etc)
- Accessible transportation
- Evacuation, shelter-in-place, and take-cover planning
- Emergency sheltering
- Access to immediate health maintenance, assistive technology, durable medical equipment, supplies, medication, oxygen, dialysis, and other resources
- Accessible emergency housing with supports and services to maintain health, safety, and independence
- Immediate and long-term accessible housing and other supports that keep people in the community, at work, in school, and connected to daily life
- Building forward (not back) to utilize disaster funding to benefit the whole community into the future

The 2019 NCD report, led by Trump-appointed NCD Chair Neil Romano, wrote:



“Once disaster survivors are institutionalized, it is difficult for them to return to the community. Sometimes, survivors who have been institutionalized cannot be located by loved ones, allies, and advocates. Additionally, the accompanying health deterioration that often accompanies institutional placement usually leads to the need for a more complex array of services while community resources have been depleted and previous support systems remain disrupted.

Additionally, 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. 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.

Institutionalization was not first witnessed in 2017 and 2018. It repeatedly occurred in previous disasters. There will be no remedy in future disasters without sweeping changes.

Based on the findings of the report, 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.

NCD looks forward to working with the Administration, Congress, disaster-impacted people with disabilities, emergency managers, public health providers, disability community leaders, allies, and other stakeholders in ensuring that disaster-related institutionalization is eliminated and that all people with disabilities are provided equal access to emergency programs and services in the most integrated setting appropriate to their needs before, during, and after disasters.”<sup>1</sup>

NCD’s own research has already shown that promising practices include local disability organization leadership, stakeholder calls led by disabled people, disaster hotlines, and direct support that prevents institutionalization. It has also shown that local disability organizations are often the most knowledgeable sources of immediate local solutions, but that their efforts are suppressed by exclusion from disaster funds and resources.

What is needed is a national call to action that invests in disability-led infrastructure, research, training, technical assistance, monitoring, enforcement, and direct support to local disability-led organizations, CILs, and other community providers. That is how SLTTs will build emergency management plans that actually work for people with disabilities and, in turn, for the whole community.

We encourage NCD to ensure this effort goes beyond the development of a standalone toolkit and instead focuses on implementing and resourcing the recommendations it has already made.

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<https://www.ncd.gov/report/preserving-our-freedom-ending-institutionalization-of-people-with-disabilities-during-and-after-disasters/>



Respectfully submitted,  
Consortium of Constituents with Disabilities Emergency Management Task Force