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

Quantum Units Education

Affordable. Dependable. Accredited.

www.quantumunitsed.com

Executive Summary

In the process of gathering data for this report, the National Council on Disability (NCD) found that people with disabilities of all ages are institutionalized during and after disasters in assisted living facilities, rehabilitation centers, nursing homes, psychiatric institutions, and other long-term care facilities -- despite legal protections requiring that services are provided in the most integrated setting appropriate to the needs of the person. In almost every case, these disaster-impacted people were living in the community before disaster struck.

The cycle of disaster-related institutionalization begins when people with disabilities are faced with the need to evacuate in a context of community-wide lack of access planning, inadequate support, and non-existent services at local shelters. Disability bias and misunderstanding about the rights and needs of disaster-impacted people with disabilities amplify the risk of institutionalization as a solution. Despite the Department of Justice (DOJ) 2007 guidance regarding the right of people with disabilities to be served in the most integrated setting appropriate to their needs in a disaster, NCD observed that in recent disasters, people with disabilities continued to be separated from their support system and segregated from the general population.

Data shows the better use of federal dollars is to provide community-based services such as accessible shelters instead of opting for institutionalization. A 2009 NCD report titled The Cost of Deinstitutionalization: Comparing the Cost of Institution Versus Community Based Services, reported 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 monetary disparity between the two is significant and further supports NCD's recommendation that in addition to being a violation of rights, institutionalization of persons with disabilities during and after disasters is not economically sound.

The threat of disaster-related institutionalization has been an ongoing concern in the disability community for well over a decade.

The threat of disaster-related institutionalization has been an ongoing concern in the disability community for well over a decade. During Hurricane Katrina in 2005, NCD found that disaster response plans often did not include protocols to evacuate people with psychiatric disabilities. In that report, NCD considered a person with a disability to have been institutionalized if the person was living in the

community the day before the disaster and did not return to home or a similar setting after the disaster.[2] The report included recommendations to improve sheltering policies and procedures on the federal, state, and local level to ensure a better outcome for persons with disabilities during and after emergencies. Over 13 years later, NCD found that little had changed.

The frequency and intensity of extreme weather and disasters is increasing. In 2017 and 2018, there were 27 catastrophic disasters across the U.S. with over one billion dollars each in damage. According to the Federal Emergency Management Agency (FEMA), 47 million people were impacted by Hurricanes Harvey, Irma, and Maria,[3] and according to the Center for Disease Control and Prevention (CDC), an estimated 12 million of them were people with disabilities.[4]

In 2017, during Hurricane Harvey, the National Council on Independent Living reported "a disturbing trend of persons with disabilities who had lived in the community [who] were transferred to institutional settings, either due to lack of post-shelter housing options or because of the difficulties of navigating disaster recovery."[5] This trend has continued unabated, in part because the issuance of waivers by the Centers for Medicare and Medicaid (CMS) allows states to place disaster-impacted people with disabilities into institutional settings for the convenience of emergency managers and health care providers even though these individuals had not developed healthcare needs requiring hospital or nursing home level care. This report is in response to a lack of progress in ensuring that people with disabilities are not institutionalized in disasters.

47 million people were impacted by Hurricanes Harvey, Irma, and Maria, and according to the [CDC], an estimated 12 million of them were people with disabilities.

This report:

- Examines how, when, and why people with disabilities were institutionalized during and after recent disasters.
- Provides recommendations for appropriate federal agencies to mitigate institutionalization of persons with disabilities in future disasters.
- Illustrates the multiple scenarios in which people with various types of disabilities are institutionalized rather than sheltered in the community or placed back into the community following the disaster.
- Examines the systemic issues that continue to cause institutionalization of persons with disabilities, such as misperception of the abilities of people with disabilities; lack of actual physical access to shelters; insufficient staffing; and lack of expertise in shelters, leading to such problems as biased intake procedures.
- Describes efforts to obtain data that illuminates and quantifies the occurrence of this issue.
- Discusses the grave short- and-long-term physical, mental, and financial consequences that institutionalization wreaks on a person with a disability, as well as the financial burden it places on the community in contrast to the costs of in-community supports.

- Provides recommendations and promising practices that would enable federal agencies to eliminate institutionalization of persons with disabilities during future disasters.

Summary of Key Findings and Recommendations

Key Findings

People with disabilities are still being institutionalized during and after disasters. There are myriad reasons for this including:

- The Federal Government continues to issue conflicting guidelines about the institutionalization of people with disabilities. For example, the Department of Justice (DOJ) in their 2007 Americans with Disabilities Act (ADA) Tool Kit states that "people should receive services in the most integrated setting appropriate to the needs of the person, and only persons who require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital" should be placed in those more restrictive settings. In contrast, the Department of Health and Human Services (HHS) Centers for Medicare and Medicaid Services repeatedly issues waivers to their institutional placement rules during disasters, allowing states to place disaster-impacted people with disabilities in nursing homes and other institutional settings.
- People with disabilities do not have equal access to emergency and disaster-related programs and services, leading to deterioration of health and safety, and loss of independence. This occurs despite the fact that federal funds are required to be spent in compliance with the equal access requirements of the Rehabilitation Act of 1973, 29 U.S.C. § 701 et seq and the Americans With Disabilities Act of 1990 as amended, 42 USC § 12102.
- Recipients of federal funds do not have training in how to comply with the Rehabilitation Act's mandate to provide equal access when using federal dollars and do not have training in how to interact with people with disabilities without adhering to a medical-model bias that leans toward institutional placement.

Key Recommendations

- Congress should reintroduce legislation that expands upon the Readying Elders and Americans with Disabilities Inclusively for Disasters Act of 2018 (2018 READI for Disasters Act) S.3679.
- All relevant federal agencies should engage with national, state, and local coalitions of disability-led organizations and stakeholders.
- FEMA should update the National Response Plan; Federal Emergency Support Functions and Federal Interagency Operations Plans; Public Health Emergency; and all other applicable federal directives to specifically address responsibility for meeting the equal access, health maintenance, safety, and independence needs of children and adults with disabilities in order to prevent institutionalization.
- FEMA Emergency Support Function Leaders Group (ESFLG) should establish 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 evacuation, temporary housing, and disaster recovery.
- DOJ and HHS should monitor and enforce the ADA *Olmstead* integration mandate and Rehabilitation Act obligation to use federal funds in compliance with requirements to serve people in the most integrated setting appropriate to their needs.
- DOJ should monitor and enforce civil rights compliance throughout all disaster-related placement decisions made by recipients and subrecipients of federal financial assistance.
- HHS (CMS) in collaboration with all other federal entities with admission and monitoring or funding and reimbursement obligations should maintain responsibility for ensuring that all admissions to hospitals and long-term care facilities during and after disasters are monitored and that the 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.
- DOJ should monitor and enforce civil rights compliance with Titles II and III of the ADA regarding sheltering.
- DOJ and HUD should monitor and enforce compliance with obligations for emergency sheltering in a disaster consistent with all other emergency sheltering requirements under the Fair Housing Act Amendments (FHAA). (Whether the disaster shelter is considered transient or long-term, the rights of people with disabilities in these shelters should be seamlessly protected.)
- DOJ should 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 their actions resulting in institutionalization of disaster survivors.

Key Recommendations, *continued*

- FEMA should explore ways to expeditiously modify its Individual Assistance registration process to curtail the incidence of institutionalization of individuals with disabilities.
- Federal agencies with disaster response and recovery responsibilities should immediately place disability civil rights experts identified from the National Qualification System in all FEMA Joint Field Offices and Area Field Offices.
- DHS/FEMA and HHS/ACL should provide grant funds to Independent Living Centers to support disaster-impacted people with disabilities in their communities. (This funding should apply to the five Independent Living Center core services, including the obligation to prevent and divert the institutionalization of disaster-impacted people throughout disaster response and recovery.)
- Relevant federal agencies should integrate disaster-related services for veterans into 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.

Conclusion

Immediate and sustained action is required to ensure that the rights of over 61 million people with disabilities[6] equally benefit from emergency and disaster programs and services even in the most challenging days of their lives.

Introduction

Every time a hurricane makes landfall or wildfires ravage a community, people with disabilities find themselves subject to involuntary institutionalization during and after these catastrophic events, despite federal statutes prohibiting unnecessary institutionalization. Examples include:

- A young man with a spinal cord injury in North Carolina was evacuated from his flooded apartment, then he was turned away from a shelter and sent to a nursing home.
- A woman with a mobility disability in a Texas shelter gathered with a group of others with disabilities and was told that they "must" go to a nursing home. She refused and left the area. When she returned, the rest of the group was gone; no one had knowledge of their destination.
- Possibly because of shelter conditions, people in North Carolina with chronic respiratory conditions were hospitalized while staying in a 'special medical needs' shelter.

These are a few examples of people with disabilities who were living independently in the community prior to disasters that occurred in 2017-18 and who were institutionalized (or who narrowly escaped institutionalization), either by virtue of the fact that they had a disability and needed accommodations in a disaster, or because their disability had been exacerbated by lack of equal access to disaster-related programs and services.

Despite civil rights protections by federal statute prohibiting unnecessary institutionalization (and despite the specific prohibition against waiving this protection during disasters), disaster-impacted people with disabilities are frequently institutionalized during and after disasters. This report will serve as a resource for preventing institutionalization of people with disabilities during and after disasters. It will be of value to national, state/territory, county, and municipal leaders, as well as people with disabilities, allies, and other stakeholders. After providing an overview of the problem, 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.

Initially, NCD intended for this report to focus primarily on factors that lead to the institutionalization of disaster-impacted people with disabilities during and after disasters that occurred during the end of 2017 and the beginning of 2018. However, NCD amassed a wealth of additional information about the factors that led to institutionalization of people with disabilities during and after Hurricane Florence, which made landfall in North and South Carolina during September 2018 and Hurricane Michael, which made landfall

in Florida and Georgia in October 2018. This information was collected through stakeholder calls in North and South Carolina, Georgia and Florida, as well as national calls held daily for the first three weeks and then on a less frequent basis.

In each of the disasters during 2017 and 2018, many disaster-impacted people with disabilities who were previously living in the community were institutionalized during or following the disaster.

Institutionalization is often an outcome of unequal access to disaster services. Factors that may lead to unnecessary institutionalization include lack of access to power and medical necessities, including medical treatment and supplemental oxygen; medication; consumable supplies; and medical equipment. Factors also include lack of equal access to food that meets dietary needs; potable water; and services offered by federal, municipal, county, and state/territory government. Disaster-impacted people with disabilities, including older adults, are at risk of institutionalization at all points of emergency response and recovery. One key point of action which has led to institutionalization is transitioning from temporary settings to more permanent solutions, such as from a shelter to temporary housing. Institutionalization is also more likely when returning home is delayed or impossible because of extended disruption in services or the significant damage to the home or community.

People with disabilities have legal protections under the Rehabilitation Act of 1973, 29 U.S.C. § 701 et seq (Rehab Act); the Americans with Disabilities Act of 1990 as amended 42 U.S.C. § 12101, et seq (ADA); and the Stafford Act, 42 U.S.C. §5151 et seq. Under the ADA, as interpreted through the *Olmstead* Supreme Court Decision *(Olmstead v. L.C.,* 527 U.S. 581), people with disabilities have the right to equal access to disaster-related services and must not be institutionalized when they may receive services in a more integrated setting that is appropriate to their needs. This means there is an obligation on the part of the Federal Government and recipients and subrecipients of federal funds to provide equal access to federally funded programs and services, including disaster-related programs and services, under the Rehabilitation Act. Additionally, there is an obligation to provide equal access to disaster-related programs and services under the ADA.

[T]here is an obligation on the part of the Federal Government and recipients and subrecipients of federal funds to provide equal access to federally funded programs and services, including disaster-related programs and services, under the Rehabilitation Act. Additionally, there is an obligation to provide equal access to disaster-related programs and services under the ADA.

Federal funding is used throughout preparedness, response, recovery and mitigation. Local decisions on how to allocate those federal funds directly correlates to persons with disabilities being institutionalized during and after disasters.

"Entities selected to receive a grant, cooperative agreement, or other award of Federal financial assistance from the U.S. Department of Homeland Security (DHS) or one of its Components, including State Administering Agencies must comply with civil rights obligations. Sub recipients have the same obligations as their primary recipient to comply with applicable civil rights requirements and should follow their primary recipient's procedures regarding the compliance with civil rights obligations."[7]

Subrecipients of federal funds routinely include entities that provide emergency protective measures for life saving and life sustaining needs and the ongoing disaster-related needs of disability impacted people with disabilities. These include local government, shelter operators, transportation services, hospitals, medical providers and many other emergency support providers.

Recommendation: NCD recommends that Congress enact legislation by expansion of the previously introduced 2018 Real Emergency Access for Aging and Disability Inclusion in Disasters (READI for Disasters Act), and the 2019 Real Emergency Access for Aging and Disability Inclusion in Disasters Act (REAADI in Disasters Act).

Recommendation: NCD recommends Congress request a report from the Government Accountability Office (GAO) to investigate whether past federal disaster funds have been used to ensure accessibility to emergency programs and services.

Recommendation: NCD recommends that DOJ provide pointed guidance to sister federal agencies to address the issue of outdated regulations that conflict with the Olmstead integration mandate.

Recommendation: NCD recommends that DOJ assesses the equal access and non-discrimination civil rights compliance of the American Red Cross and other shelter and mass care providers in relation to actions resulting in institutionalization of disaster survivors.

When people with disabilities do not have equal access to disaster-related programs and services, an array of cascading events occur that may lead to institutionalization. Existing systems crumble; health may deteriorate; effective communication for people with visual, hearing, cognitive, and speech disabilities ceases; and other systemic gaps are exacerbated. For example, a disaster-impacted person chooses to shelter in place because the community shelter does not have wheelchair-accessible restrooms. This person's health deteriorates in their badly damaged home, resulting in a need for hospitalization, which results in institutionalization. A less apparent example is a lack of qualified sign language interpreters that results in shelter staff referring a Deaf person to a psychiatric institution because the person is assumed to have a mental

health condition rather than a need for an interpreter. Lack of equal access to disaster-related programs and services is not only a violation of the law, but a fundamental precursor to institutionalization. As discussed above, institutionalization may constitute a violation of disability civil rights law when services may alternatively be provided in a more integrated setting.

Once a disaster survivor is 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 is inherent in institutional placement leads to the need for a more complex array of services while community resources have been depleted and previous support systems remain disrupted.

Institutionalization is a phenomenon not only witnessed in 2017 and 2018. It has occurred repeatedly in previous disasters. There is no indication that this will be remedied in future disasters without sweeping changes. These changes must occur through planning, implementation, monitoring, and enforcement of federal obligations to provide equal access. They must include physical, program, and effective communication access, as well as modifications to policies, practices and procedures to avoid discrimination before, during and after disasters.

Lack of equal access to disaster-related programs and services is not only a violation of the law, but a fundamental precursor to institutionalization.

Institutionalization of people with disabilities in disasters indicates failure on multiple levels of the government, of NGOs, and other collaborators who share the responsibility of providing equal access to emergency services and programs to disaster-impacted people with disabilities in their communities. This report examines the matrix of misunderstanding, miscommunication, contradiction, and deficient public policy that leads to wrongful institutionalization of people with disabilities during and after disasters; it also proposes actions that, if implemented, may eliminate potentially discriminatory practices.

Chapter 1: Occurrence of people with disabilities being institutionalized during and after disasters

This report examines occurrences of institutionalization of people with disabilities, as well as threats of institutionalization that were thwarted by disability advocates, in 2017 and 2018. The disasters included Hurricanes Harvey, Irma, Maria, Florence, and Michael, and the California wildfires. During these time periods, the NCD research team was alerted via disaster hotline calls and stakeholder teleconferences that people with disabilities were being referred and admitted to institutions, as well as being threatened with institutionalization.

In preparing this report, the NCD research team interviewed key informants from FEMA; Red Cross; municipal offices for people with disabilities; Centers for Independent Living; State/Territory Independent Living Councils; State and Territory Protection and Advocacy systems; and State/Territory University Centers for Excellence in Developmental Disability. Most key informants agreed that people with disabilities were institutionalized during and after disasters. One key informant from the U.S. Virgin Islands reported that he was more aware of untimely, preventable death in the aftermath of the hurricanes than the occurrence of institutionalization. He referenced the hundreds of people who were evacuated to Puerto Rico during Hurricane Irma, and then further evacuated to Atlanta, Georgia after dialysis delivery and other medical systems failed during Hurricane Maria. This informant pointed out that many had not returned. Informants reported that many of those who did survive were placed in long-term care facilities even though they had previously lived independently in the community.

NCD conducted two focus groups comprised of disaster survivors and key informants from disability organizations. Special attempts were made to enlist input from disaster survivors who were institutionalized or threatened with institutionalization. Stakeholders advised that these people were reluctant to discuss their harrowing and traumatic experiences. Further outreach efforts were immediately halted to avoid re-traumatization.

Throughout each focus group discussion, participants concurred that people with disabilities were institutionalized during and after disasters. One stakeholder reported advocating for a Texas resident who was threatened with guardianship in order to hold him against his will in a nursing home. This attempt at forced institutionalization was thwarted by attorneys from the Texas Protection and Advocacy System. During the focus group conducted in Puerto Rico, key informants reported that disaster-impacted people with disabilities weren't institutionalized primarily

because institutions weren't functioning. Because hospitals also weren't functioning, they were not used for sheltering, either; indeed, many evacuated their patients to the mainland. One group of young children who required uninterrupted power for medical devices were evacuated by private air services, coordinated by hospital physicians, to Florida and Texas. When they arrived on the mainland, they learned they were ineligible for hospital admission simply for access to an uninterrupted power source; they had nowhere else to go and at least one parent was threatened with having her child removed from her care and placed in a nursing facility because she (the evacuated parent) was considered homeless. Additionally, the parent was advised that their Puerto Rico-issued Medicaid was not portable and they were not eligible for Florida Medicaid since they did not reside in the state prior to the disaster. To make matters worse, when advocates asked FEMA to assist this family, they were told, during a national stakeholder call, that the family was ineligible for FEMA assistance because they had not evacuated 'correctly.' The lack of Medicaid portability repeatedly came up on stakeholders' calls and was mentioned by key informants from Puerto Rico, the U.S. Virgin Islands and Florida (including during Hurricane Michael evacuation) as a critical issue that was impeding health care for disaster impacted people with disabilities. Denial of Medicaid coverage can cause people with disabilities to lose their health, safety and independence, which may ultimately lead to hospitalization and nursing home admission.

Recommendation: NCD recommends that Congress require CMS to establish a process for Medicaid portability among states and territories during disasters to ensure uninterrupted health maintenance and medical care in the least restrictive environment for Medicaid recipients.

One group of young children [from Puerto Rico] who required uninterrupted power for medical devices were evacuated … to Florida and Texas. [One] parent was advised that their Puerto Rico-issued Medicaid was not portable and they were not eligible for Florida Medicaid since they did not reside in the state prior to the disaster.

The National Council on Independent Living (NCIL) developed a report in the fall of 2017 on Hurricane Harvey stating that, "There was a disturbing trend of people with disabilities who had lived in the community being transferred to institutional settings, either due to lack of post-shelter housing options or due to the difficulties of navigating disaster recovery."[8]

Even though unnecessary institutionalization of people with disabilities may constitute a violation of civil rights that cannot be waived, the Federal Government sanctioned it by issuing waivers through CMS. The purpose of the waivers was to expedite admission of people to nursing homes based on hospital needs, sheltering needs, and other factors

completely unrelated to the health and well-being of people with disabilities. This topic is discussed in Chapter 3. Clearly, people with disabilities were institutionalized during and after disasters as a direct result of these waivers.

Specific instances of institutionalization that surfaced during the development of this report and the After-Action Report are alarming. Equally alarming is the likelihood that many never-identified people with disabilities were also institutionalized. Several key informants and focus group members stated that the process of identifying and locating people with disabilities who were institutionalized during disasters may take years. For example, CNN reported that Jefferson County, Texas Judge Jeff Branick stated that "One thousand people with special needs [were] taken to Galveston airport and will be removed to other locations for 'specialized care.'"[9] There is no available information as to their outcome or their location. Such circumstances are particularly likely for people who do not communicate verbally and/or have intellectual or cognitive disabilities, such as dementia.

Disaster-impacted people with disabilities get separated from family, friends, and neighbors when they go to segregated 'special needs'/'special medical needs' shelters. After separation, loved ones may not know when the person left the shelter and the name and location of the institution to which the person with a disability was sent.

Disaster hotline callers reported that people with disabilities were escorted en masse out of the George R. Brown Center, a general population community shelter, without a clear idea of where they were going and possibly without the opportunity to tell family members and friends in the shelter that they were leaving. As frequently reported during stakeholder teleconferences, a similar situation occurred in Bay County, Florida during Hurricane Michael at both general and 'special needs' shelters.

Disaster-impacted people with disabilities get separated from family, friends, and neighbors when they go to segregated 'special needs'/'special medical needs' shelters. After separation, loved ones may not know when the person left the shelter and the name and location of the institution to which the person with a disability was sent. Information about where people with disabilities were sent or discharged to is not consistently tracked and shared by shelters, Disaster Medical Assistance Teams, Red Cross, emergency managers, or any other entity. In fact, key informants report that sometimes there is no record of transfers at all. One key informant mused that if logistics companies can track packages with precision, we should be able to track disaster-impacted people with disabilities at least as well.

Lack of tracking and notification to families, combined with inadequate data, make documenting the number of people with disabilities institutionalized during and after disasters a challenge, if not impossible. For example, CMS Minimum Data Set surveys do not identify or track nursing home admissions during evacuation; the period of CMS 1519 waivers; and other disaster-associated circumstances during and after a disaster. States and territories do not track this data, either.

In preparing this report, NCD sought to obtain, compile, and analyze data about the movement of disaster-impacted people with disabilities to hospitals, nursing homes, assisted living facilities, and other institutional care settings. NCD requested via phone and in writing all relevant data from several federal and state agencies involved in the movement, relocation, placement, care, or funding of disaster-impacted people. Data was requested from: DHS; FEMA; HHS; CMS; ACL; Office of the Assistant Secretary for Preparedness and Response (ASPR); CDC; Long-Term Care Ombudsman's Offices in Texas, Florida, U.S. Virgin Islands, and Puerto Rico.

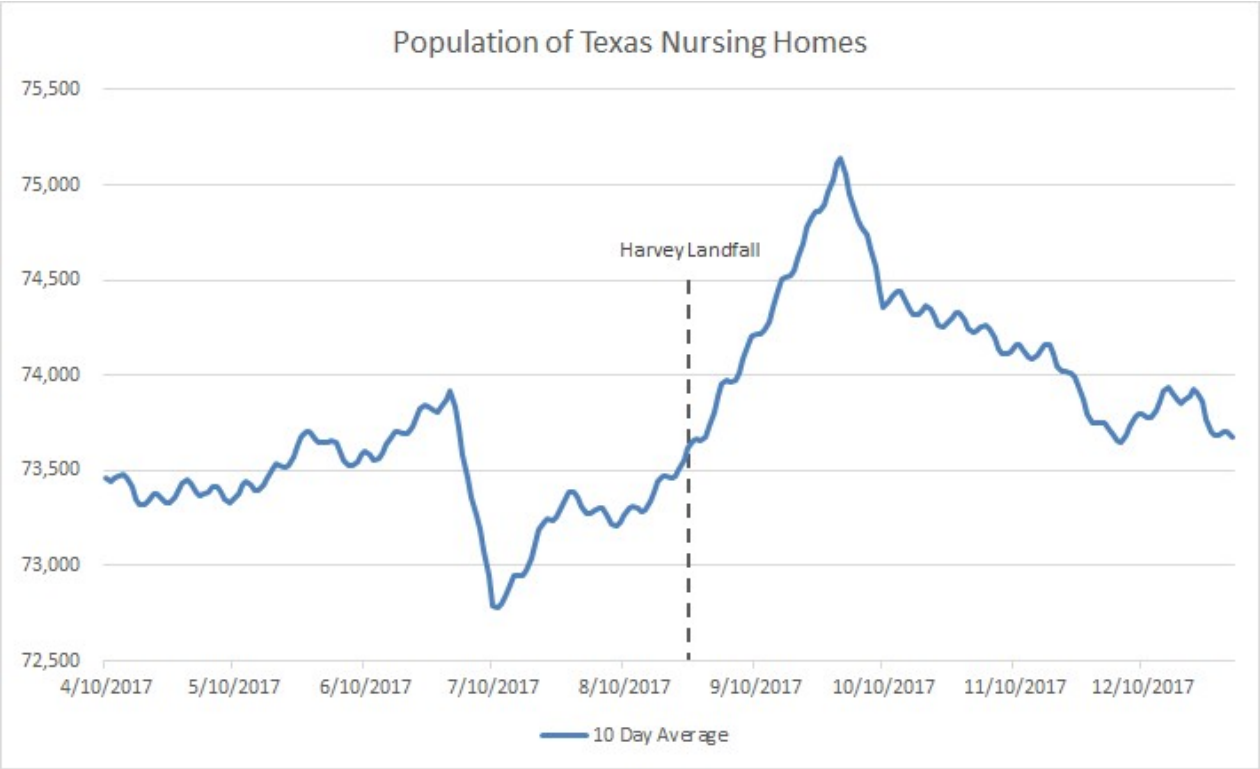
NCD submitted Freedom of Information Act requests to CMS and to each federal office, followed by a request from the chairman of NCD. These letters appear in the Appendix. The aforementioned agencies, except ACL, either responded stating they had no data or did not respond at all to NCD's data request.

However, NCD was able to locate publicly available data indicating significant increases in nursing home census numbers after Hurricanes Harvey and Irma.

In the absence of data from entities providing services and/or payment, NCD accessed the data available on the HHS CMS website. That data lacked sufficient specificity for the purpose of this research.

However, NCD was able to locate publicly available data indicating significant increases in nursing home census numbers after Hurricanes Harvey and Irma.

Graph 1

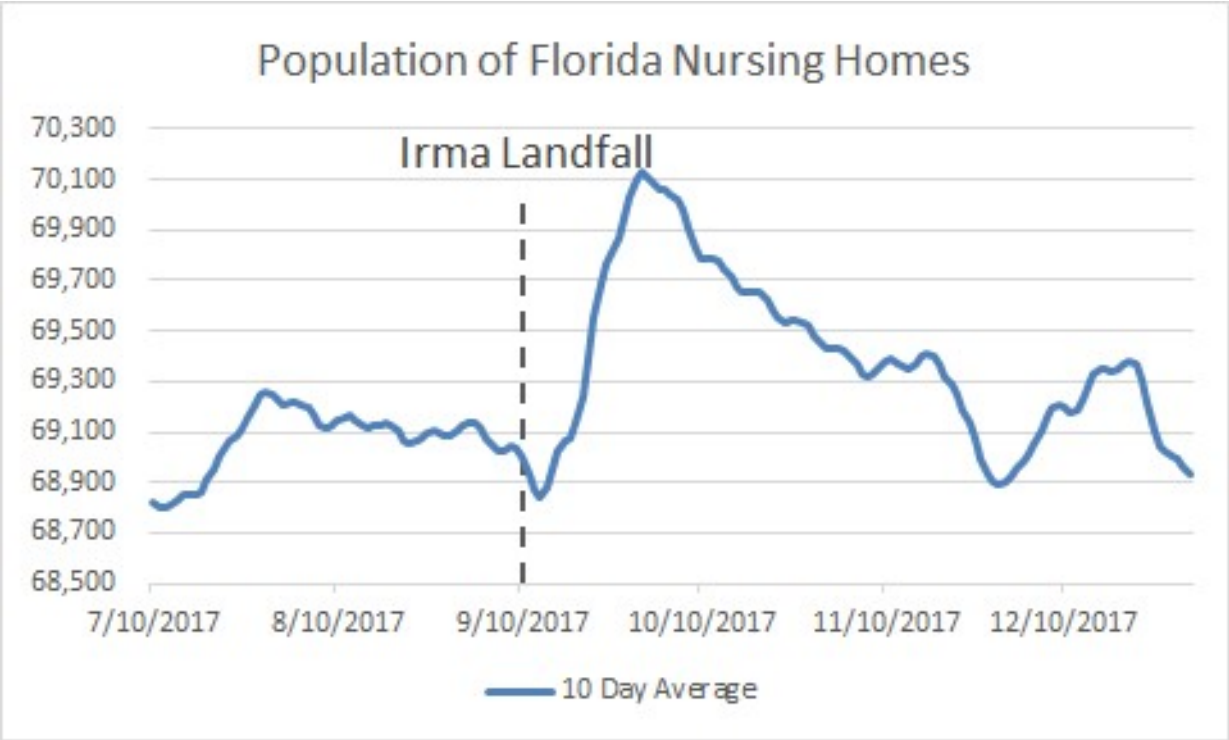


See [10], [11], and [12]

Nursing home admissions after Hurricane Harvey (TX)

Graph 1 shows an uptick in nursing home admissions after Hurricane Harvey made landfall in Texas. There are brief downticks that coincide with the Thanksgiving and Christmas holidays. Data in this graph reflects only the nursing facilities which reported data for all quarters covered in the chart.

Graph 2

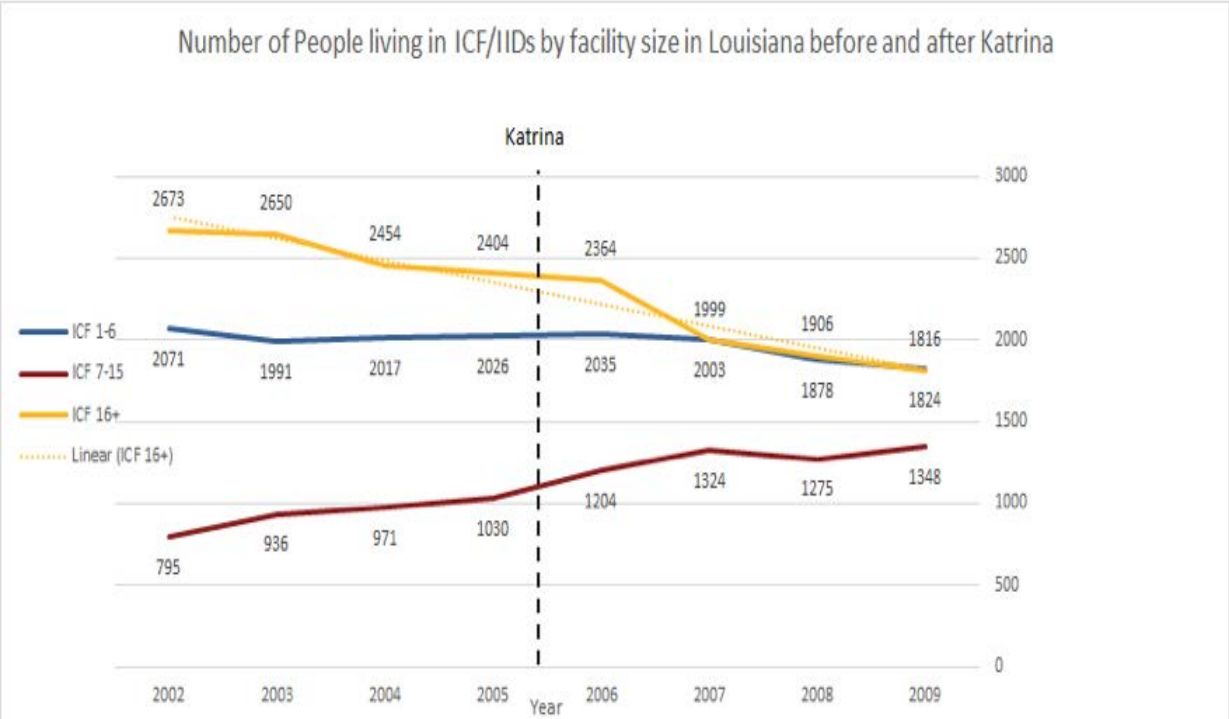


See [13], [14], and [15]

Nursing home admissions after Hurricane Irma (FL)

Graph 2 shows an uptick in nursing home admissions after Hurricane Irma made landfall in Florida. Data in this graph reflects only the nursing facilities which reported data for all quarters covered in the chart.

Graph 3



See [16]

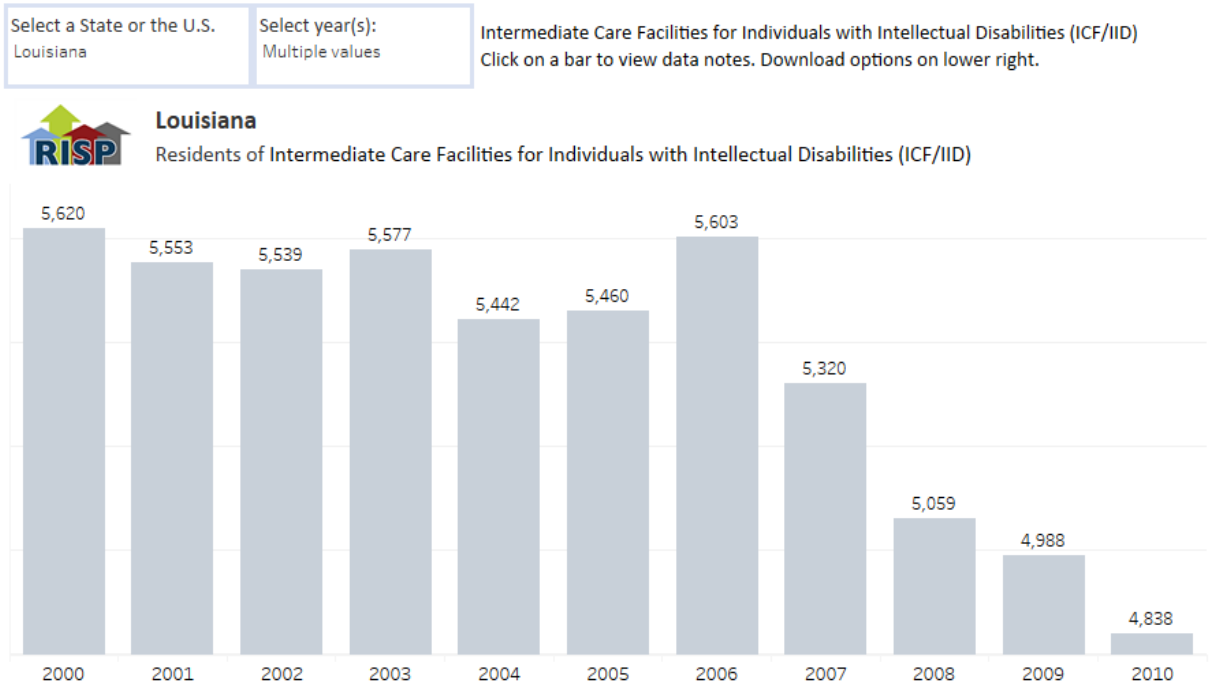
Utilization of institutional care associated with Hurricane Katrina (LA)

NCD also obtained material from the University of Minnesota Institute on Community Integration University Center on Excellence in Disabilities Residential Information Systems Project (RISP) describing findings of increased institutionalization of people with intellectual and developmental disabilities impacted by Hurricane Katrina in 2005.

The findings from the RISP showed that there was a measurable change in utilization of Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) of 7 or more and 16 or more people in Louisiana associated with Hurricane Katrina. (See Graph 3)[17]

- Between 2002 and 2005, the number of people in ICF/IID facilities of 16 or more people **declined** by an average of 90 people per year. Between June 30, 2005 and June 30, 2006, the number declined by only 40 people. Between 2006 and 2009, the number **declined** by an average of 183 people per year.[18]
- Between 2002 and 2005, the number of people in ICF/IID settings of 7 to 15 people **declined** by an average of 11 people per year. Between June 30, 2005 and June 30, 2006, the number **increased** by 134 people. Between 2006 and 2009, the number **declined** by an average of 135 people per year.[19]

Graph 4



See [20]

Graph 4 clearly illustrates the disruption of deinstitutionalization caused by Hurricane Katrina and the increase in ICF/IID facility placement to levels equal in numbers from the initiation of deinstitutionalization in 2000.[21]

Hurricane Katrina temporarily disrupted the deinstitutionalization process in Louisiana after making landfall on August 29, 2005. This slowed the rate of downsizing for ICF/IID facilities of 16 or more people, and temporarily increased the use of ICF/IID settings of 7 to 15 people.[22]

Interviews, disaster hotline calls, and teleconferences produced many examples of institutionalization and threats of institutionalization of people with disabilities. In North Carolina during Hurricane Florence, people with mobility disabilities were admitted to nursing homes because they could not get access to health maintenance services, such as physical therapies, in their communities. People with Chronic Obstructive Pulmonary Disease (COPD) and other respiratory conditions were admitted to hospitals after staying in a segregated shelter.

Recommendation: NCD recommends that HHS provides funding to 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.

In South Carolina, also during Hurricane Florence, an emergency manager suggested that a person requiring a personal care assistant be institutionalized if that person was not able to identify personal care assistants who would provide care during sheltering.

During Hurricane Harvey, a woman in Texas with a mental health disability was institutionalized ostensibly because of trauma from the disaster. She was discharged from the hospital with prescriptions for which she could not afford the copay. By the time a disaster hotline operator persuaded the pharmacy to accept a credit card, she was re-institutionalized.

A disaster hotline caller from Texas who had been in the George R. Brown Convention Center shelter after Hurricane Harvey was told she was being sent to a nursing home with a group of other shelter residents. She refused and left the area. When she returned, the others were gone. No one knew where they had been sent. Another disaster hotline caller requested assistance for several people who had been evacuated to a nursing home several hundred miles from their Texas residence. No accessible transportation was provided for the return trip to their undamaged home. The people were unable to leave the nursing home until funding for their transportation was secured.

Key informants in Puerto Rico reported that local hospitals became de facto shelters for people with disabilities when they had nowhere else to go during Hurricane Maria. Others in Puerto Rico and the U.S. Virgin Islands reported that the loved ones of people with disabilities who evacuated from the territories in Hurricane Maria still could not account for their relatives with disabilities.

Others in Puerto Rico and the U.S. Virgin Islands reported that the loved ones of people with disabilities who evacuated from the territories in Hurricane Maria still could not account for their relatives with disabilities.

Key informants in Florida expressed concerns that Hurricanes Irma and Michael survivors with disabilities were transferred to assisted living or nursing facilities upon discharge from 'special needs' shelters. The informants reported that they were unable to track the whereabouts of these survivors. A disaster hotline caller from Florida reported that she was forced to institutionalize a relative whom she was caring for because his care needs were too great once their home was destroyed.

During and after Hurricane Michael, people with disabilities were moved from shelter to shelter, and frequently placed in assisted living facilities across the state. Independent Living Center staff repeatedly attempted to keep track of and maintain contact, however staff members were routinely denied information about movement, as well as access to the people with disabilities and the location of the facilities in which they were housed.

There are consistent indicators of the use of institutional placement for disaster-impacted people with disabilities coupled with the lack of any system or process for documenting displacement.

Recommendation: NCD recommends that Congress appropriate funds for FEMA, HHS (ACF and ACL) and HUD to fund Independent Living Center staff 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.

After Hurricane Michael, people with disabilities in Florida who were offered Temporary Sheltering Assistance in hotels and other settings by FEMA were not provided personal assistant services, accessible transportation, and other required accommodations, rendering them unable to maintain health, safety, and independence and subjecting them to hospitalization and institutionalization.

Recommendation: NCD recommends that Congress require that HHS establish a data collection system and that data collection begins immediately after the next federally declared disaster. The system must identify impacted individuals moved to an institutional setting and quantify movement and displacement of all impacted people in the aggregate.

It is likely that the people described above would not have been institutionalized if their right to equal access to federally-funded disaster-related programs and services and their right to receive services in the most integrated setting had been provided.

Chapter 2: The detriments of institutionalizing people with disabilities during and after disasters

Institutionalization of people with disabilities during and after disasters is detrimental on multiple levels. It robs people with disabilities of autonomy; may be a violation of their civil rights; and may produce negative health outcomes. In addition to impacting personal resiliency, it also impacts family and community resiliency.

Loss of freedom, independence, and equal opportunity

The civil rights of people with disabilities are protected under the Rehabilitation Act, the ADA, and the Stafford Act. Not only is unnecessary institutionalization a breach of the autonomy of disaster survivors with disabilities, it is prohibited under Title II of the ADA as interpreted in the *Olmstead* Supreme Court decision. Under *Olmstead,* people with disabilities must receive services in the setting most appropriate for that person. Failure to provide people with disabilities equal access to disaster-related programs and services may be a violation of the equal rights provisions of the ADA, Rehabilitation Act, Stafford Act, and state/territory disability rights laws. Further, civil rights are not suspended during disasters, as explicitly confirmed in the National Preparedness System and its frameworks.[23]

"Entities selected to receive a grant, cooperative agreement, or other award of federal financial assistance from the U.S. Department of Homeland Security (DHS) or one of its components, including State Administering Agencies, must comply with civil rights obligations. Subrecipients have the same obligations as their primary recipient to comply with applicable civil rights requirements and should follow their primary recipient's procedures regarding the compliance with civil rights obligations."[24]

Of all the potential denials of equal opportunity, unnecessary institutionalization constitutes the greatest deprivation of liberty. Institutionalization of people with disabilities during and after disasters is typically not the result of a single failure of equal opportunity. It is more often the result of a series of failures to provide a person with equal access to disaster-related programs and services throughout the disaster process.

Of all the potential denials of equal opportunity, unnecessary institutionalization constitutes the greatest deprivation of liberty.

By the time a person reaches the point of being unnecessarily institutionalized, they have likely had their civil rights violated repeatedly, and intensively. Violations that lead to institutionalization often arise on a local level as a result of poor planning, which includes knocks on doors to notify Deaf people of an evacuation; requiring people with mobility and stamina issues to wait in line for food and water; and lack of durable medical equipment in shelters. These denials of equal opportunity, particularly when combined with other denials of equal opportunity, may result in institutionalization. In order to prevent unnecessary institutionalization, equal access to disaster-related programs and services must be addressed on a local, county, state/territory, and national level. In addition to being deprived of equal access to disaster-related programs and services, disaster-impacted people with disabilities are impacted by broad social inequities and policy deficiencies, including poverty and the lack of affordable, accessible housing.

Declines in health, well-being, and morbidity upon institutionalization during and after disasters

The trend over the past several decades has been to close and move people out of psychiatric institutions and institutions for people with intellectual and developmental disabilities. Evidence shows that nursing homes are particularly dangerous places to live during disasters. The U.S. Senate report *"Sheltering in Danger: How Poor Emergency Planning and Response Put Nursing Home Residents at Risk During Hurricanes Harvey and Irma" (November 2018)* addressed the dangers people in nursing

homes and assisted living facilities face during and after disasters.[25] These factors are discussed in more detail in the section that follows.

Several studies indicate that people have a higher quality of life in the community than in nursing homes. One study found that "Residents of institutions more often reported problems with mobility, selfcare and usual activities."[26] Another study found that "older adults with cognitive impairment living at home experienced higher quality of life, had better cognitive function, were less depressed, and reported higher social connectedness compared to those living in institutional care."[27] A separate study of people who had been approved for nursing home placement reported that "findings from this study continue to show that the majority of older adults in our sample were able to maintain community tenure following an application for nursing facility placement. In addition, the unexpectedly high rates of successful community tenure have been realized without intensive use of state publicly funded services."[28] Other documentation clearly demonstrates that people with disabilities have a strong preference for living in the community.[29]

Another study found that "older adults with cognitive impairment living at home experienced higher quality of life, had better cognitive function, were less depressed, and reported higher social connectedness compared to those living in institutional care."

To improve the opportunity for people with disabilities to live in the community, Congress passed—and CMS implemented—Money Follows the Person (MFP), a Rebalancing Demonstration Grant that has supported over 75,000 people[30] to move out of nursing homes and back into the community. MFP was established in recognition of people's strong preference to live in the community; the obligation under the *Olmstead* decision to provide service in the most integrated setting appropriate to the needs of the person with a disability; and the great cost savings of community living. The unnecessary institutionalization of disaster-impacted people with disabilities flies in the face of the *Olmstead* decision, it goes against the national policy to rebalance service delivery in favor of home and community based services, which are more cost-effective, preferred by people with disabilities, and in compliance with anti-discrimination law.

The dangers of institutions for people with disabilities in disasters

Institutions are dangerous for people with disabilities during and after disasters. Media outlets widely reported poor conditions in nursing homes and assisted living facilities that led to deteriorated health, injury, and death during and after the 2017 disasters.[31] A photo taken of residents of the Bella Vita assisted living facility in Dickinson, Texas, waist deep in flood water

following Hurricane Harvey, garnered widespread attention.[32]

The dangers associated with living in nursing homes and assisted living facilities during and after Hurricanes Harvey and Irma in Texas and Florida are corroborated in the Senate Report (November 2018), noted above. The report's "investigation cataloged a series of missteps, poor emergency planning, and faulty communication strategies that contributed to the misery and the preventable deaths of nursing home residents."[33] Findings in Texas include that "the evacuation of the Lake Arthur Place nursing home was marked by the use of physical force, intimidation, and ultimately physical restraint by local law enforcement officers. At the La Vita Bella assisted living facility residents spent hours in waist-deep water waiting for help."[34]

A photo taken of residents of the Bella Vita assisted living facility in Dickinson, Texas, waist deep in flood water following Hurricane Harvey, garnered widespread attention.

The findings cited failures in Florida that led to the death of 12 residents of the Rehabilitation Center at Hollywood Hills "[resulting] from inadequate regulation and oversight, ineffective planning and communications protocols, and questionable decision-making by facility administrators."[35] The report states that "the 12 deaths at Hollywood Hills were ruled homicides by the Broward County Medical Examiner."[36] many of the deaths were preventable and were a direct result of criminal negligence.

Even the process of being transported to an institution may lead to death. This risk was illustrated in Horry County, South Carolina following Hurricane Florence. Two women, Wendy Newton and Nicolette Green, drowned in the back of a sheriff's van while being transported to a psychiatric institution after having been civilly committed. Under court order, the women were involuntarily transported from a safe place through an area where there was known to be significant flooding. The deputies transporting the women were rescued when they were found unharmed on the roof of the sheriff's transport vehicle; the women, however, remained trapped inside.[37] After an investigation, both deputies were fired.[38] This incident raised questions about law enforcement engaging in transport of people with medical needs. [39] As of publication, the incident remains under investigation.

Even the process of being transported to an institution may lead to death.

Economic consequences of institutionalization

Anecdotal evidence shows that people with mobility disabilities, autism, intellectual disabilities, actual or perceived psychiatric disabilities, dementia, brain injury, and COPD and respiratory disabilities have been unnecessarily institutionalized during disasters in a variety of facilities.

The types of institutions that people with

disabilities are most commonly admitted to during and after disasters are nursing homes, sometimes euphemized as rehabilitation centers. People are also involuntarily committed or threatened with involuntary commitment to psychiatric institutions during and after disasters. Stakeholder teleconferences, disaster hotline calls, and general media coverage revealed that some people were threatened with commitment under what is known as the Baker Act (Florida Statute 394.451-394.47891), Florida's involuntary commitment statute. People experiencing homelessness immediately prior to Hurricane Harvey were threatened with civil commitment if they did not report to a shelter. For reasons delineated below, people choose to shelter in place for valid reasons, including inability to manage themselves in crowded conditions and noise, and mistrust of government. As noted above, a disaster hotline caller from Texas was readmitted to a psychiatric institution because she was not able to fill the prescription she had been given after the disaster. In a post-Irma Florida listening session, another woman reported being threatened with civil commitment when she was refused admission to a nursing home because of the psychiatric medication that she took. In this situation, advocates intervened, and she was not committed.

Working people with disabilities who are institutionalized during and after disasters become unemployed. Should they seek another job upon discharge from the institution, they may have a difficult time securing employment because of stigma and because their community is coping with the economic effects of a recent disaster.

Even those who are not employed play valued social roles in the community and their absence, through institutionalization, will impact community resilience and result in economic loss to the person, their family, and their community. Institutionalization of people with disabilities who are caregivers could result in the institutionalization of their aging parents or spouses and other family members with disabilities for whom they care. The institutionalization of people who care for children or grandchildren results in a childcare crisis for an already traumatized family. Such a situation could result in job loss for the non-institutionalized parent or the placement of children in foster care, all resulting in economic loss.

Working people with disabilities who are institutionalized during and after disasters become unemployed.

One senior executive at a major oil company in Texas who is the parent of a child with autism attributed her inability to resume work after Hurricane Harvey to the lack of child care and transportation from their temporary housing location to her child's school, which was now several hours away. The relocation of the family's in-home support providers resulted in the loss of that essential service. The school district offered residential care so the mother could resume employment, an illustration of multilayered economic ramifications.

Disaster-impacted students with disabilities have legal protections under the Individuals with Disabilities Education Act (IDEA) of 1975, the ADA, and the Rehabilitation Act. Having such services and supports in place when students with disabilities return to school would help to ensure equal access to their education and allow their parents and guardians to return to work. Immediate action to return students with disabilities to school with their peers also will minimize the risk of institutionalization.

Communities cannot be resilient in disastersunless all its members are resilient. Institutionalization of people with disabilities weakens overall community resilience and negatively impacts local economies.

Recommendation: NCD recommends that the U.S. Department of Education (ED) issue a policy directive to require school systems to include an individualized emergency plan for uninterrupted delivery in every student's IEP or 504 plan to comply with the Free and Appropriate Public Education requirement in IDEA and in the Rehabilitation Act.

Recommendation: NCD recommends that ED takes immediate action to ensure that disaster-impacted students with disabilities are not excluded from 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.

Chapter 3: Why people with disabilities end up institutionalized during and after disasters

Factors that lead to institutionalization during and after disasters

The failure to provide equal access to disaster-related services, resulting in institutionalization, is not limited to a specific point in disaster response and recovery, nor is institutionalization limited to a specific disability group or groups. Virtually all the factors that lead to institutionalization can be anticipated and institutionalization prevented.

The chart that follows demonstrates the factors that individually or collectively drive institutional admissions beginning at evacuation, and throughout disaster response and recovery. Some factors occur during one phase of the disaster cycle; others occur across multiple phases. A more thorough examination of several of these factors follows at the end of Chapter 3.

Factor	Preparedness	Response	Recovery
Entrenched medical model of disability and disability bias	X	X	X
Failure to plan, poor planning, and non-execution or faulty execution of plans	X	X	
Lack of understanding of the legal obligation to provide equal access to programs and services when using acquired federal funds. Examples include accessible notifications, warnings, transportation, housing, etc.	X	X	X
Lack of understanding that assisted living facilities are institutions that, because they are less regulated, pose their own risks	X	X	X
Notifications and warnings that are not accessible to people with disabilities		X	
Lack of communication between evacuation and shelter personnel		X	

Factor	Preparedness	Response	Recovery
Limited ability to bring the person's needed assistive devices, technology, and accommodations		X	
Difficulty of applying for FEMA services or receiving reasonable accommodations		X	X
Lack of backup power in shelters	X	X	
Confusion among government entities about the use of hospital and nursing home placement in disasters	X	X	X
Unrealistic expectations about caregivers, personal assistance providers, etc.	X	X	X
Separation of people with disabilities from their natural supports		X	X
Loss of durable medical equipment, consumable medical equipment, and assistive technology		X	X
Deterioration of health because of, for example, lack of conditions conducive to health maintenance		X	X
Disagreements among first responders, shelter operators, medical professionals, local/state/federal personnel	X	X	X
Movement of people with disabilities to multiple sheltering locations		X	
Sending people with disabilities to locations, such as hotels, that are not prepared to interact with disaster-impacted people		X	X
Messaging that may portray lack of disability supports and services throughout evacuation and sheltering	X	X	
Failure to embrace "dignity of risk" and self-determination	X	X	X

Factor	Preparedness	Response	Recovery
Lack of Medicaid portability between home and host states and territories		X	X

Although there are numerous factors that lead to institutionalization during and after disasters, all are rooted in the medical model of disability; poor planning; and lack of understanding of civil rights laws that protect people with disabilities during and after disasters.

Medical model of disability

Scholars have written about the medical model of disability since the 1960s. People who have adopted the medical model of disability make assumptions that people with disabilities are sick and that optimal services for people with disabilities are provided by medical professionals. Adherents to this model hold a paternalistic perspective that people with disabilities need protection. They also believe, consciously or subconsciously, that it is the job of people without disabilities to keep people with disabilities safe, often in a medical environment. Many responders and people in the field of public health adhere to at least some of the components of the medical model of disability.

Ineffective, poorly executed, and non-existent planning

Poor planning was another consistent factor that contributed to lack of equal access in disaster-related programs and services, ineffective, poorly executed, and non-existent planning was evident throughout all stages of all the disasters. Examples include:

- Red Cross did not conduct access surveys of shelters prior to disasters, resulting in people with mobility disabilities lacking accessible toilets for long periods in many areas and without accessible showers for months in the U.S. Virgin Islands.
- Shelter staff did not have a mechanism to provide information about people with disabilities who were discharged, removed, or relocated from shelters and were admitted to nursing homes.
- CMS did not have a process for collecting information and data regarding whether a person was admitted to a nursing home during a disaster and whether that person was subsequently returned to a more integrated setting.
- Poorly resourced and trained local and county emergency managers were responsible for decisions involving referrals of disaster-impacted people with disabilities to institutions and subsequently securing permanent housing in the most integrated setting appropriate to their needs.

Lack of compliance with and understanding of disability rights law

Emergency responders, managers, and even some members of the disability community consistently demonstrated a lack of understanding that federally-funded disaster-related programs and services must be accessible under the Rehabilitation Act and that these rights cannot be waived. They also lacked an appreciation for the rights that people with disabilities have under the ADA to equal access to disaster-related programs and services and to receive services in the most integrated setting appropriate to their needs. It appeared that many saw the practice of institutionalization and the denial of equal access to disaster-related programs and services that could lead to institutionalization as acceptable occurrences. Many either did not appreciate or did not articulate that these practices are unlawful. It also appeared that many did not appreciate how closely the lack of equal access to disaster-related programs and services was linked to institutionalization. And, even among highly knowledgeable community leaders, the option of institutionalization seemed an acceptable solution considering the circumstances, eschewing

[E]ven among highly knowledgeable community leaders, the option of institutionalization seemed an acceptable solution considering the circumstances, eschewing planning as an issue to be dealt with after the disaster.

planning as an issue to be dealt with *after* the disaster.

At times, responders showed a lack of urgency to avoid institutionalizing people with disabilities during and after disasters. One emergency manager maintained that if a personal assistant could not be found for a disaster survivor with a disability, institutionalization would be required. Although the emergency manager stated that this course would be followed only in a worst-case scenario (and stakeholders from the disability community stated, in response, that they sincerely hoped that institutionalization would not happen), no one brought up that such an eventuality might be unlawful.

Recommendation: NCD recommends federal entities require that all recipients and subrecipients of federal funds receive training in the scope of their obligations to people with disabilities. 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.

Recommendation: NCD recommends federal entities monitor recipients and subrecipients of federal funds to ensure compliance throughout all disaster related placement decisions by recipients and subrecipients of federal financial funds.

Recommendation: NCD recommends that federal agencies with any responsibility for emergency preparedness, community resilience, and disaster-related services, programs, supports, or activities must engage with national, state, and local coalitions of disability-led organizations and stakeholders. These federal agencies include but are not limited to: DHS FEMA, Office for Civil Rights and Civil Liberties, HHS, ASPR, ACL, Administration for Children and Families, Independent Living Administration, CDC, HUD, Department of Transportation, DOJ, Disability Rights Section, ED, Office of Special Education and Rehabilitative Services, Department of Labor, Office of Disability Employment Policy, Department of Defense, Veterans Affairs, and U.S. Access Board.

Recommendation: NCD recommends that each agency publish an annual report documenting its engagement on its website.

In order to prevent unnecessary institutionalization, federal guidance must be consistent with the ADA and other applicable civil rights laws, as well as consistent between agencies. Additionally, implementation must be geared towards preserving the safety of people with disabilities in ways that also preserve their civil rights.

Conflicting guidance from federal agencies

State/territory and local governments are rightly confused about their obligations to provide services to disaster survivors with disabilities in the most integrated setting appropriate to the survivor. This confusion stems from the lack of alignment of guidance documents with the *Olmstead* ADA integration mandate as it applies to people with disabilities impacted by disasters.[40]

In 2007, DOJ instructed state and local governments in their ADA Best Practices Tool Kit for State and Local Governments, Chapter 7 that "The ADA requires people with disabilities to be accommodated in the most integrated setting appropriate to their needs, and the disability-related needs of people who are not medically fragile can typically be met in a mass care shelter.[41] For this reason, people with disabilities should generally be housed with their families, friends, and neighbors in mass care shelters and not be diverted to special needs or medical shelters."

"The ADA requires emergency managers and shelter operators to accommodate people with disabilities in the most integrated setting appropriate to their needs, which is typically a mass care shelter Local governments and shelter operators may not make eligibility for mass care shelters dependent on a person's ability to bring his or her own personal care attendant."[42] This is consistent with the integration mandate in the *Olmstead* Supreme Court decision.

Unfortunately, however, numerous other guidance documents from other federal agencies are in conflict with this DOJ language. Excerpts from these conflicting current federal guidance documents are included in the pages that follow.

Department of Justice (DOJ)

"Shelters are usually divided into two categories: (1) 'mass care 'shelters, which serve the general population, and (2) 'special needs 'or 'medical 'shelters, which provide a heightened level of medical care for people who are medically fragile. Special needs and medical shelters are intended to house people who require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital."[43]

Department of Homeland Security (DHS)

Office for Civil Rights and Civil Liberties (CRCL)

"Under federal civil rights laws, sheltering services and facilities must be accessible to children and adults with disabilities. Sheltering and temporary housing of persons with disabilities must take place in the most integrated setting appropriate to the needs of the person, which in most cases is the same setting people without disabilities enjoy. The intent of this federal guidance is to ensure that people are provided appropriate accommodations and are not turned away or moved from general population shelters and temporary housing or inappropriately placed in other, more restrictive, environments (e.g., 'special needs' shelters, institutions, nursing homes, and hotels and motels disconnected from other support services)."[44]

Federal Emergency Management Agency (FEMA)

Segregating children and adults with and without disabilities who have access or functional needs from general population shelters to "special

needs" shelters is ineffective in achieving equitable program access. Additionally, if a special needs shelter is the only choice given to a person with a disability, it violates federal law.[45] People with disabilities are entitled by law to equal opportunity to participate in programs, services, and activities in the most integrated setting appropriate to the needs of the person. Additionally, children and adults with and without disabilities who have access and functional needs should not be sheltered separately from their families, friends, and/or caregivers because services they require are not available to them in general population shelters.[46]

[I]f a special needs shelter is the only choice given to a person with a disability, it violates federal law.

"[P]roviders must be aware that they may fall into more than one category of provider. For example, a state agency that receives federal financial assistance must comply with laws and regulations that apply to federal financial assistance recipients as well as to laws that apply to state and local governments. Non-profit organizations that receive federal financial assistance to provide food, clothing, shelter, or transportation in connection with an emergency must comply with obligations applicable to recipients of such assistance as well as requirements generally applicable to nonprofit organizations that provide services to the public."[47]

Department of Health and Human Services (HHS)

Office for Civil Rights (OCR)

"Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts will help ensure that responsible officials are in compliance with Federal civil rights laws and that the disaster management in the affected areas by Hurricane Florence is successful."[48]

[I]t instructs that when an individual is institutionalized in a disaster, the goal is to return them to the least restrictive environment, without referring to the legal obligation …

Although this guidance contains "equal opportunity to benefit" language from the ADA, it neither provides instruction as to how to provide equal opportunity nor reflects any of the *Olmstead* integration mandate.

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

The Office of the Assistant Secretary for Preparedness and Response published "Working with Older Adults and People with Disabilities: Tips for Treatment and Discharge Planning" during the 2017 disaster response reminding responders and healthcare providers not to institutionalize disaster-impacted people with disabilities who did not reside in institutional settings before the disaster, however it instructs that when an individual is

institutionalized in a disaster, the goal is to return them to the least restrictive environment, without referring to the legal obligation to meet the needs of disaster-impacted individuals in the most integrated setting appropriate to the needs of the individual.[49]

Centers for Disease Control and Prevention (CDC)

"Somewhere between a temporary shelter and temporary hospital, a Federal Medical Station is a non-emergency medical center set up during a natural disaster to care for displaced persons with special health needs—including those with chronic health conditions, limited mobility, or common mental health issues—that cannot be met in a shelter for the general population during an incident."[50]

This guidance runs contrary to the *Olmstead* integration mandate and to the guidance from the Federal Government agencies above. It would allow referral of people with disabilities to a Federal Medical Station if they have "special health needs that include chronic health conditions, limited mobility, or common mental health issues."

People with disabilities often take the following actions as a consequence of conflicting guidance:

- Choose to remain in harm's way, even in a mandatory evacuation, rather than evacuate to 'special medical needs' shelters, hospitals, and nursing homes that are unable to provide the disability assistance they require.
- Evacuate then are denied access to general population community shelters and are transferred (often against their will) to 'special medical needs shelters' or directly to hospitals and nursing homes even though they do not require hospitalization or nursing home care.
- Are denied access to community sheltering and are often admitted to hospitals and nursing homes without discharge plans, and sometimes remain institutionalized in these facilities long after the disaster has ended.
- Encounter inadequate emergency plans for sheltering in place and evacuation at "special medical needs" shelters. For example, a "special medical needs" shelter planned to evacuate sheltered people with disabilities and bariatric needs housed on the 3rd floor by using "bed sleds."
- Are forced to pay for their evacuation and sheltering (whether in a hotel or in a hospital) even though others who stay in the community shelters benefit from government-funded transportation and sheltering at no personal cost. Evacuated veterans with disabilities were billed for their hospitalizations in one example of this disparity.

The failure to provide equal access to community shelters harms not only people with disabilities, but also communities with limited acute care beds; first responders; and skilled medical professionals when they are needed most.

Centers for Medicare and Medicaid (CMS)

During Hurricanes Harvey, Irma, Maria, Florence and Michael and the California wildfires of 2018, HHS issued waivers through CMS that, among other things, allowed for:

- Movement of disaster-impacted people to skilled nursing facilities (SNFs) from hospitals to "make room for more seriously ill patients"
- Placement of disaster-impacted people with disabilities in a SNF "as a result of the emergency"

"Section 1812(f) of the Social Security Act (the Act) authorizes the Secretary to grant SNF coverage in the absence of a qualifying hospital stay, as long as this action does not increase total program payments and does not alter the SNF benefit's "acute care nature" (that is, its orientation toward relatively short-term and intensive care).

"Under this authority, CMS can issue a temporary waiver of the SNF benefits qualifying hospital stay requirement for those beneficiaries who are evacuated or transferred as a result of the emergency situation. In this way, beneficiaries who may have been discharged from a hospital early to make room for more seriously ill patients will be eligible for Medicare Part A SNF benefits. In addition, beneficiaries who had not been in a hospital or SNF prior to being evacuated, but who need SNF care as a result of the emergency, will be eligible for Medicare Part A SNF coverage without having to meet the 3-day qualifying hospital stay requirement."[51]

These waivers conflict with the integration mandate in the U.S. Supreme Court *Olmstead* decision and federal guidance from DOJ, DHS and FEMA on serving people with disabilities in the most integrated setting appropriate to the person, including in a disaster. There are no waivers to civil rights in disasters or disaster loopholes.

These CMS waivers are also not consistent with statements made by the HHS Office for Civil Rights, as seen in their September 13, 2018 press release and the technical assistance HHS provides. "Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts will help ensure that responsible officials are in compliance with Federal civil rights laws and that the disaster management in the areas affected by Hurricane Florence is successful."[52]

There are no waivers to civil rights in disasters or disaster loopholes.

The CMS waivers cited above conflict with the placement of people with disabilities in the most integrated setting appropriate to their needs. It is important to point out though that not all CMS waivers are detrimental to compliance with most integrated setting obligations to provide services in the most integrated setting appropriate to the needs of the person. In fact, these waivers can assist in the prevention of institutionalization of disaster-impacted people with disabilities. For example, CMS states that "when durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS) are lost, destroyed, irreparably damaged, or otherwise rendered unusable due to

circumstances relating to a declared emergency, Medicare will pay for the replacement DMEPOS that a Medicare beneficiary owns or purchased. Examples include home oxygen equipment, continuous positive airway pressure (CPAP) devices and supplies, hospital beds, diabetes testing supplies, wheelchairs, canes, walkers, artificial limbs, braces, and enteral nutrients and supplies. CMS can exercise allowable flexibilities and issue waivers (when authorized) as necessary to accommodate the needs of those impacted by an emergency or disaster."[53]

It is indisputable that people with disabilities are placed in institutions during and after disasters and that certain conflicting federal policies allow this scenario, as evidenced by recent CMS technical assistance documents and practices that waive civil rights protections by expediting nursing home admissions. This practice occurs despite guidance from DOJ requiring state and local governments to provide assistance to people with disabilities in the most integrated setting appropriate to the needs of that person. These protections include the disaster-related sheltering needs of people with disabilities who "don't require the type and level of medical care that would ordinarily be provided by trained medical personnel in a nursing home or hospital."[54]

Using blanket waivers in disasters to place people with disabilities in nursing homes is a violation of the Federal Government's own directives on civil rights compliance.

Using blanket waivers in disasters to place people with disabilities in nursing homes is a violation of the Federal Government's own directives on civil rights compliance. Yet, this practice is common and continues, disregarding the civil rights of people with disabilities.

Implementation shortfalls of emergency support functions

Another failure that leads to institutionalization is the approach taken by the Federal Government to assist the states in disaster response. When a state exceeds its capacity to meet the emergency needs of its residents or if it anticipates a lack of capacity, the governor will declare a disaster and request assistance from the President. If granted, the Federal Government will initiate several emergency support functions (ESFs) under which to provide assistance. One of the ESFs with a very significant effect on the needs of disaster-impacted people with disabilities is ESF #8. ESF #8 "provides the mechanism for federal assistance to supplement local, state, tribal, territorial, and insular area resources in response to a disaster, emergency, or incident that may lead to a public health, medical, behavioral, or human service emergency, including those that have international implications." It "provides planning and coordination of federal public health, healthcare delivery, and emergency response systems to minimize and/or prevent health emergencies from occurring; detect and characterize health incidents; provide medical care and human services to those affected; reduce the public health and human service effects on the community; and enhance community resilience to respond to a disaster." ESF #8 addresses "public

health and medical services (e.g., patient movement, patient care, and behavioral healthcare) and [delivery of] support to human services (e.g., addressing people with disabilities and others with access and functional needs) through surge capabilities that augment public health, medical, behavioral, and veterinary functions with health professionals and pharmaceuticals. These services include distribution and delivery of medical countermeasures, equipment and supplies, and technical assistance. This ESF may continue providing services and ensure a smooth transition to recovery while the community rebuilds its capability and assumes administrative and operational responsibility for services." ESF #8 provides supplemental assistance to local, state, tribal, territorial, and insular area governments. This assistance includes the role of ESF #8 and ASPR in some of their core functional areas, which include:

- Assessment of public health/medical needs
- Health surveillance
- Medical surge
- Health/medical/veterinary equipment and supplies
- Patient movement
- Patient care
- All-hazards public health and medical consultation, technical assistance, and support
- Behavioral healthcare
- Public health and medical information[55]

Limitations and shortfalls in the implementation of ESF #8 by ASPR have limited the removal of barriers to equal access to health maintenance in the most integrated setting appropriate. These barriers may result in institutionalization of disaster-impacted people with disabilities.

Barriers to equal opportunity to receive health care and ESF #8 services from HHS were among the most devastating gaps repeatedly reported by stakeholders, key informants, and disaster hotline callers. These gaps were also consistently reported in traditional and social media.

For example, one recurrent problem that was never resolved was the provision of oxygen to disaster survivors in Puerto Rico who were not in acute medical settings. Reportedly, over 50,000 people living in the community across Puerto Rico use oxygen for maintaining their health and independence. Oxygen was previously manufactured and supplied on the island and provided to residents. When the manufacturing capability was indefinitely disrupted, there was no plan for providing an alternative source. This critical life-saving and life-sustaining medical need seemed to fall squarely within the responsibility of ESF #8. However, because the focus of ASPR's efforts were on establishing hospital and medical facility operation, there was no effort to meet the health maintenance needs of thousands of disaster survivors who depend on receiving oxygen outside of medical facilities.

When the U.S. Naval Ship Comfort arrived, it

was assumed that its oxygen manufacturing capability would be used to meet these needs. Instead, it quickly became apparent that the hospital ship was only providing oxygen for facility-based care, further eliminating any immediate resources for non-institutional provision to disaster survivors with disabilities. The outcome for the people left on the island without access to oxygen is unknown.

Another gap in ESF #8 was the incomplete process of serving the dialysis and related needs of disaster-impacted people from the U.S. Virgin Islands. Approximately 200 people requiring dialysis and their companions were evacuated from the U.S. Virgin Islands to San Juan, Puerto Rico, during Hurricane Irma. These people were then evacuated to Atlanta, Georgia, in anticipation of Hurricane Maria's landfall on Puerto Rico. These people were provided with hotel rooms and dialysis services, but it became apparent that their other needs and the needs of their companions had not been considered. Intervention from government and non-government resources were required to address basic needs such as food, transportation for non-dialysis needs (such as trips to the grocery store), and disability-related medical equipment and supplies. For many of these people, the gaps in service delivery and lack of coordination resulted in health deterioration, shortfalls in meeting needs, and overreliance on hospitalization. Over one year later, many of these people are still in Atlanta, and their future remains in limbo. This lack of cohesiveness is just one of the factors that lead to institutionalization as an eventual 'solution.

When representatives from Paralyzed Veterans of America (PVA) traveled to assess the needs of their members in Puerto Rico days following Hurricane Maria, they reported that a significant gap in coordination between services from the Veterans Administration and other disaster related health care providers duplicating some services and denying others. PVA reports that this gap appears to exist routinely throughout disaster response.

Recommendation: NCD recommends that FEMA 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.

While the responsibility for ESF #8 falls to HHS, the overall leadership for the coordination of all of the Emergency Support Functions is held by FEMA through their Emergency Support Function Leadership Group (ESFLG) "The Federal ESFs bring together the capabilities of Federal departments and agencies and other national-level assets. ESFs are not based on the capabilities of a single department or agency, and the functions for which they are responsible cannot be accomplished by any single department or agency. Instead, Federal ESFs are groups of organizations that work together to deliver core capabilities and support an effective response. The ESFLG comprises the Federal departments and agencies that are designated as coordinators for ESFs or coordinating agencies for other NRF annexes.

FEMA leads the ESFLG and is responsible for calling meetings and other administrative functions."[56]

Recommendation: NCD recommends that FEMAs ESFLG establish 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 evacuation, temporary housing, and disaster recovery.

Disability stakeholder organizations meet daily during disaster response and weekly after the immediate response period has passed. Personnel from FEMA, ASPR, CLA, the DHS Office for Civil Rights and Civil Liberties, and other key federal agencies are invited to each of these meetings, but only representatives from DHS Office for Civil Rights and Civil Liberties routinely attend. Lack of engagement and participation from agencies limits coordinated efforts to address and resolve the immediate needs of disaster-impacted people with disabilities, disability organizations, and other disaster service providers. During the Hurricane Florence response, ASPR leadership told Congressman Bennie Thompson's staff that they would assign a representative to engage with disability organizations, but never responded to further outreach efforts.

Lack of engagement and participation from agencies limits coordinated efforts to address and resolve the immediate needs of disaster-impacted people with disabilities, disability organizations, and other disaster service providers.

Recommendation: NCD recommends that the Veterans Administration and HHS collaborate 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.

The Post-Katrina Emergency Management Reform Act (PKEMRA) (Pub. L. 109-295 required FEMA to consult with NCD and other organizations to appoint a Disability Coordinator, who is to ensure that the needs of individuals with disabilities are being properly addressed in emergency preparedness and disaster relief. Additionally, FEMA's duties include: interacting with NCD and other stakeholders regarding the needs of individuals with disabilities in emergency planning requirements and relief efforts in case of disaster; revising and updating guidelines for government disaster emergency preparedness; carrying out a national training program to implement the national preparedness goal; assessing the nation's prevention capabilities;

identifying and sharing best practices; developing, coordinating and maintaining a National Disaster Housing Strategy; developing accessibility guidelines for communications and programs in shelters and recovery centers; and helping all levels of government in the identification of shelter locations and capabilities when a recipient uses preparedness grant assistance when developing and maintaining evacuation plans.

Recommendation: NCD recommends that Congress amend the Stafford Act to require HHS to have active engagement with disability organizations with specific expertise and involvement in national disability inclusive emergency management policy and practice. The provision should be similar to those in PKEMRA requiring community engagement by FEMA.

Further examination of factors that lead to institutionalization disconnects and bureaucratic quagmires occur repeatedly throughout the disaster cycle and have an impact on people with disabilities that may contribute to institutionalization. Conditions before, during and following a disaster can lead to unnecessary institutionalization that may persist long after people without disabilities have been able to return to their day-to-day lives.

Poverty and low income

Poverty is at the heart of pre-disaster circumstances that may trigger a cascade of events leading to institutionalization of disaster-impacted people. The fewer resources people and families have, the less likely they are to be able to mitigate factors leading to institutionalization. Losing one's home or experiencing homelessness puts people with disabilities at greater risk of unnecessary institutionalization.

For example, it was reported on stakeholder calls that landlords in Panama City, Florida after Hurricane Michael were attempting to force large numbers of people to leave low-income habitable apartments with only 74-hours' notice. Although legal remedies were sought, some people left because landlords threatened to withhold security deposits if tenants did not comply with eviction. It has been speculated that landlords were evicting low-income tenants so that they could refurbish units with insurance or disaster recovery funds and raise rents substantially.

People who live in poverty are more likely to live in substandard housing, which is more vulnerable in a disaster because of location and quality of building materials. In addition, people who live in poverty are disproportionately impacted by evacuation orders. Even when their property is not damaged or destroyed, they may face eviction because they cannot pay rent upon returning home because all their funds were expended on evacuation-related expenses. Then, having been evicted, they lose their security deposit and credit, both of which are critical to obtaining new housing. All these

The fewer resources people and families have, the less likely they are to be able to mitigate factors leading to institutionalization.

conditions may lead to institutionalization.

Recommendation: NCD recommends that Congress 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.

Although people with disabilities are among those with the highest rates of poverty, it is critical to note that they are often members of other marginalized groups, including people of color, LGBTQ, and women, thus increasing the likelihood that they live in poverty. For a variety of reasons, this intersectionality may result in higher rates of institutionalization.

Inaccessible alerts, warnings, and notifications

People with disabilities are frequently criticized, blamed and shamed when they do not evacuate during a mandatory evacuation. This refusal or inability to evacuate is sometimes a response to a lack of disaster-related programs and services and other public policy failures. People may choose to shelter in place because they lack actionable information about when to evacuate, how to evacuate, and where to go. For instance, notifications and warnings are frequently not accessible to people who are Deaf even if captioning or interpreters are provided., because often captions and interpreting is blocked from being seen on screen.

Alerts direct people with disabilities to shelter in place or direct them to environments that may be too loud, lack privacy or lack an accessible bathroom. Messages may instruct people with disabilities who need personal assistance that they must bring a personal assistant with them. However, they may not be able to afford an assistant at that time or may not have a personal assistant available for an unspecified amount of time. Conversely, people with disabilities referred to most "special needs" shelters are often only allowed to have one family member stay with them. This requires parents with disabilities who have more than one child to separate from them, risking loss of custody to child protective services. In addition, people with disabilities may harbor a distrust of government because of lack of access to and discrimination by government programs and services in the past.

[N]otifications and warnings are frequently not accessible to people who are Deaf even if captioning or interpreters are provided, because often captions and interpreting is blocked from being seen on screen.

Recommendation: NCD recommends that the Federal Communications Commission (FCC) reestablish their 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 the Department of Justice.

Registries

NCD cannot overstate how detrimental registries for people with disabilities are in disasters.[57] Stakeholders across the spectrum of disability advocates and emergency managers still struggle to find ways to make registries a viable solution to identify, rescue and evacuate people with disabilities affected by disasters despite repeated failures of registries. Registries isolate and marginalize people with disabilities and create a false sense of expectation among people with disabilities and their family members. Like institutions, registries have been proven to be an ineffective method to ensure proper evacuation and sheltering of people with disabilities during emergencies.

Registries isolate and marginalize people with disabilities and create a false sense of expectation among people with disabilities and their family members.

People with disabilities have a right to equal access to emergency services. Registries have both impeded equal access solutions and established inadequate alternatives for using federal funds. NCD recommends that no federal funds, including but not limited to federal funds from the U.S. Department of Homeland Security and the U.S. Department of Health and Human Services, be used in development, deployment, and maintenance of emergency 'special needs' registries intended to include people with disabilities.

Evacuation

In addition to lack of equal access to notification and notifications, many people with disabilities do not have equal access to the evacuation process itself. When evacuations are required prior to shelter openings, people with disabilities are often forced to find accessible places to stay outside the evacuation zone. If accessible hotels are available, people with disabilities often do not have money to stay in them. In addition, accessible transportation out of the evacuation zone is often not available to people who require it or, when available, it is costlier than the standard transportation deployed for other evacuees.

Numerous disaster hotline callers reported that, after evacuation, they were homeless or facing homelessness because they used all their available funds on hotel stays and meals, a factor that could lead to institutionalization. In addition, disaster hotline callers reported that they chose to shelter in place

because they were unable to reach 911, 211, or 311 for clarification of evacuation instructions.

In summary, lack of clear and affordable evacuation instructions and options for people with disabilities are often directly connected to institutionalization.

Recommendation: NCD recommends that the Federal Mass Evacuation Plan, 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.

Respite

Stakeholders reported that some people with disabilities do not get as far as sheltering before they are institutionalized. Among them are people who are institutionalized through the use of a respite placement during the disaster. Respite often becomes an eventuality when people with disabilities evacuate with family and friends to inaccessible locations. At the point of permanent placement, the family is often unable to find adequate accessible housing and the respite, which is a nursing home or other long-term care facility, becomes a permanent placement for the family member with a disability.

Recommendation: NCD recommends that HHS (CMS) in collaboration with all other federal entities with admission and monitoring or funding and reimbursement obligations maintains responsibility for ensuring that all admissions to hospitals and long-term care facilities during and after disasters are monitored and that the 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.

Disability bias and medicalization of disability

Nearly every key informant who was interviewed brought up disability bias and medicalization of disability as factors that lead to disaster survivors with disabilities not having equal access to disaster-related programs and services and being referred to segregated shelters for people with disabilities and to institutions.

The Red Cross describes one of the barriers to shelter transition as: "Medicalization of Disability—The tendency to view people with disabilities as patients in need of medical intervention, even though they are living independently in the community prior to the disaster. This can result in placement of a person into a "special needs" shelter or skilled nursing facility which removes their right to make decisions for themselves, often with grave consequences." [58]

Recommendation: NCD recommends that legislation be introduced to establish 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. The goal is to ensure that, in carrying out disaster management planning and programs, the agencies and groups address the mitigation of disability bias and inappropriate application of the medical model during and after disasters.

Key informants called for training for shelter managers, staff, and volunteers to have intensive training on mitigating conscious and unconscious disability bias and perceiving and interacting with disaster survivors with disabilities through the lens of the medical model. In addition, informants recommended that training be provided in concepts like the dignity of risk and self-determination. Key informants stated that a large part of the problem is that public health nurses and other professionals are trained that their number one priority must be to keep people with disabilities safe. Their discipline correlates safety with placement in a medical environment, which in their view is safer for people with disabilities.

Key informants called for training for shelter managers, staff, and volunteers to have intensive training on mitigating conscious and unconscious disability bias …

Placement Decisions

Throughout evacuation, sheltering and transitioning from shelters and temporary housing, decisions about the placement of people with disabilities are almost always deferred to the local emergency manager. In most cases, local emergency management offices are significantly understaffed. During disasters, the array of their responsibilities is massive, and they are rarely knowledgeable about the rights of people with disabilities, the alternatives to institutionalization, or their own responsibilities regarding the obligation to place in the most integrated setting. They may not have any familiarity with disability resources in their community and may likely have been trained in approaches that perpetuate disability bias and medical model solutions. The middle of a disaster is far too late for education, and reliance on institutional solutions is far too easy.

The funding for local emergency management operations are typically generated by the Federal Government and subsequently funneled through state and county grants, contracts, and subcontracts. Under the Rehabilitation Act, acceptance of federal funding creates an obligation to ensure that placement of people with disabilities complies with civil rights obligations.

Recommendation: NCD recommends that the federal entity (typically FEMA and DHS) providing the funds ultimately received by local emergency management departments requires the participation of local staff in training on the scope of obligations under the Rehabilitation Act.

Recommendation: NCD recommends that DOJ monitor and enforce civil rights compliance throughout all disaster-related placement decisions made by recipients and subrecipients of federal financial assistance.

Sheltering

The period of evacuation and temporary sheltering before, during and following disasters brings circumstances that lead to the institutionalization of disaster survivors with disabilities. Disaster survivors with disabilities are often institutionalized after they enter an unprepared or poorly staffed general population/mass care/community shelter or following placement in 'medical special needs' shelters, 'medical friendly' shelters,' 'special needs shelters,' and 'Federal Medical Stations.' Institutionalization also occurs when survivors seek assistance in acute care hospitals.

A HUD frequently-asked-question document delineates the differences between integrated and segregated environments. It states that "One of the basic tenets of Section 504 is that programs and services be conducted in the most integrated setting appropriate to the needs of the individual with a disability.[59] In terms of housing, this means that the housing provided to people with disabilities is not separate or unnecessarily segregated from housing provided to people without disabilities. Integrated settings also enable people with disabilities to live independently with disabilities and without restrictive rules that limit their activities or impede their ability to interact with people without disabilities. Examples of integrated settings can include scattered-site apartments providing permanent supportive housing, tenant-based rental assistance that enables people with disabilities to lease housing in integrated developments, and apartments for individuals with various disabilities scattered throughout public and multifamily housing developments.

"By contrast, segregated settings are occupied exclusively or primarily by people with disabilities. Segregated settings sometimes have qualities of an institutional nature, including, but not limited to, regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, limits on peoples' ability to engage freely in community activities, and manage their own activities of daily living, or daytime activities primarily with other people with disabilities."[60]

According to DOJ, the issue of "special needs", "special medical needs", "medical friendly", was settled as far back as the *Olmstead* decision and clearly described in the 2007 ADA Toolkit: "The ADA requires people with disabilities to be accommodated in the most integrated setting appropriate to their needs, and the

disability-related needs of people who are not medically fragile can typically be met in a mass care shelter. For this reason, people with disabilities should generally be housed with their families, friends, and neighbors in mass care shelters and not be diverted to special needs or medical shelters".

General population/community shelters

People with disabilities are sometimes institutionalized when they check into a general population shelter.

Recommendation: NCD recommends that DOJ and other federal entities with enforcement authority 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.

Some of the factors that lead to institutionalization are medical model orientation and disability bias on the part of shelter staff and volunteers; lack of ability to track disaster survivors with disabilities after leaving shelters; lack of hotel room vacancies, especially for accessible hotel rooms in Transitional Sheltering Assistance (TSA)-approved hotels; and chronic lack of accessible and affordable housing in the community.

People with disabilities encountered numerous barriers in general population shelters that led to declining health and institutionalization. Barriers ranged from lack of accessible showers to policies that limited access. One general population shelter was made physically inaccessible by not allowing people with mobility disabilities access to an elevator, the only path to the restrooms, without what was described as a "chaperone" in the evening. There were seldom enough "chaperones" to escort people with mobility disabilities in the elevator to the restroom. This led to deteriorating health from incontinence and other effects of not being able to use a toilet.

All places of public accommodation, including shelters, are required to comply with Title III of the ADA. State and local government entities are required to comply with Title II of the ADA in its programs, including shelters. DOJ has the authority to enforce these obligations.

Segregated shelters

Institutions and segregated shelters (also known as 'medical special needs shelters,' 'medical friendly shelters,' 'special needs shelters,' and 'Federal Medical Stations' for people with disabilities) are perceived by public health professionals and others as a mechanism for keeping people with disabilities safe, an impression held despite the fact that disaster-impacted people were living successfully in the community prior to the disaster. Training should focus on the fact that actual safety is contingent on autonomy and self-determination rather than on isolating people with disabilities in congregate settings, even though the latter perspective is a more comfortable one for medically oriented caregivers.

Recommendation: NCD recommends that the Department of Justice monitor and enforce civil rights compliance with Titles II and III of the ADA regarding sheltering.

Recommendation: NCD recommends that DOJ and HUD monitor and enforce compliance with obligations for emergency sheltering in a disaster consistent with emergency sheltering requirements under the Fair Housing Amendments Act. Whether the disaster shelter is considered transient or long-term, the rights of people with disabilities in these shelters should be seamlessly protected.

Recommendation: NCD recommends that DOJ 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.

Examples of public health professionals referring disaster-impacted people with disabilities to the more restrictive environment of segregated shelters were abundant on daily stakeholder calls held in the wake of Hurricane Florence. Stakeholders reported that Emergency Management Assistance Compact (EMAC) nurses from a state that routinely uses 'special needs' shelters repeatedly referred people to segregated shelters when they should have been referred to and provided reasonable accommodations in general community shelters. It was reported that EMAC nurses "did not understand the way that we do things in North Carolina."

Across disasters, shelter managers and public health professionals had a tolerance for institutionalization that is inconsistent with the *Olmstead* integration mandate. Many saw institutionalization as less than optimal, but were willing to use it as a "last resort."

An article in the *North Carolina Health News* described the people at a "medical needs shelter" as follows: "Patients were mostly those with chronic diseases, ranging from people in hospital beds to a young man with a recent spinal cord injury, or a pair of older sisters, one blind, the other on a walker, who needed a little more than what a regular shelter could provide."[61] The author of this article seems to have adopted the medical model of disability, conflating people who have acute medical needs with people who have disabilities and need assistance to maintain their health, safety, and independence.

Segregated shelters institutionalize people with disabilities for the same reasons that general shelters do. It is easier for people with disabilities to get "lost" within the institutional system once they have been separated from friends, family, and neighbors, and health may deteriorate in segregated shelters.

Segregated facilities are not appropriate to meet the disaster-related sheltering needs of people with disabilities who "don't require the type and level of medical care that would ordinarily

be provided by trained medical personnel in a nursing home or hospital." [62] These shelters have obligations under the ADA and, because most of such facilities receive federal funds, they also have obligations under the Rehabilitation Act.

Decision-making regarding who, when, and why disaster survivors with disabilities end up in segregated shelters requires those making decisions to interpret complex and contradictory sets of guidance from multiple federal agencies (DOJ, DHS, HHS). It is difficult to imagine how lawmakers, local government emergency managers, and shelter operators could arrive at decisions about who goes to segregated shelters in anything but an arbitrary way.

It seems clear that separating disaster-impacted people with disabilities from family, friends, and neighbors runs in deep contradiction to the *Olmstead* integration mandate to provide services in the most integrated setting appropriate. Emergency managers often believe "special needs" and "medical shelters" offer better conditions, including backup power and air conditioning. However, designated shelters for people with disabilities often have conditions that are worse than general population shelters. Like institutions, segregated shelters tend to offer inadequate services. Key stakeholders have reported that the movement of people from evacuation to shelters, emergency rooms, hospitals, and long-term care facilities are not recorded with any consistency or by using any connected tracking systems. Red Cross tracks their own shelter census information, but this data doesn't follow people moved among shelters. The National Disaster Medical System uses a very sophisticated Department of Defense "patient movement system", but this system does not share connectivity with any civilian systems. This failure is further compromised by the disconnect between Emergency Support Functions #6 (Mass Care) and Emergency Support Function #8 (Public Health and Medical Services). Currently, there is no systemic approach to the movement of people with disabilities taken out of general population settings during disaster cycle phases. The cycle begins with alerts, then proceeds through evacuation, sheltering, health maintenance, medical care, temporary housing, return home/permanent housing, resumption of work/school, and re-entry to functioning community systems and supports. Reliable tracking is especially important when people with disabilities are separated from family, placed in segregated shelters, or in any other way served differently than disaster-impacted people who don't have disabilities.

Because special needs registries are at best ineffective and at worst misused to steer people with disabilities into institutions.

Recommendation: NCD recommends that no federal funds-- including but not limited to federal funds from the U.S. Department of Homeland Security and the U.S. Department of Health and Human Services--be used in development, deployment, and maintenance of emergency 'special needs' registries exclusively created for people with disabilities.

Recommendation: NCD recommends that legislation be introduced to establish required documentation of all movement from the community, emergency shelters, and other general population settings to hospitals, nursing homes, assisted living, long-term care, rehabilitation, psychiatric institutions, hospice, and other medical facilities. Documentation should also include any movement among any of these community, institutional and medical facilities. The legislation should include specific mandates for CMS to act to ensure that each person (inclusive of people not receiving Medicare or Medicaid services) is provided with all of the services and supports required for successful return to the most integrated setting appropriate to their needs.

A lack of backup power for operating medical equipment in general community shelters is another planning failure that often leads to segregated sheltering. In some states, people needing backup power for c-pap, bi-pap, power wheelchairs, scooters, and other medical or assistive devices can only be accommodated in 'special medical needs' shelters due to lack of backup power plants throughout the shelter system. Even then, in North Carolina, during Hurricane Florence, people were expected to "bring their own backup power and connectors" to the 'special medical needs' shelters. In South Carolina, backup power was only available in 'special medical' shelters, however people were told that they would only be admitted if they brought their own caregivers, and that despite the descriptor of "medical needs shelters," the level of care provided was described as "medical monitoring." Key informants reported that medical care was not provided in virtually every 'medical' shelter opened during the period from 2017-2018 (and earlier).[63]

A lack of backup power for operating medical equipment in general community shelters is another planning failure that often leads to segregated sheltering.

The existing requirements in the CMS Emergency Preparedness Rule published by CMS in 2016 requires that backup power is provided in every long-term care facility. The National Sheltering System does not include any similar requirements or tracking of the availability of backup power.[64]

Recommendation: NCD recommends that the appropriate federal agency require that backup power is provided in every shelter identified throughout the National Shelter System. This requirement is like the existing requirements in the National Preparedness Rule published by CMS in 2016.[65]

One disturbing example of "special medical needs" shelters failing to meet the needs of evacuees occurred in the "special medical needs" shelter in Goldsboro, North Carolina. This shelter was in a long-closed psychiatric institution, placement in which was described as traumatic for disaster survivors and shelter advocates with psychiatric disabilities. Exacerbating the trauma typically experienced by people with psychiatric disabilities who have been institutionalized, threatened with institutionalization, or fear institutionalization was that this particular institution had been a racially segregated facility until 1965 and was threatened with loss of federal funding in 2008 after alleged neglect led to the death of a resident.[66] For reasons that remain unclear, people who stayed in this shelter who had COPD and other respiratory conditions experienced exacerbation of their conditions so great that they required admission to a hospital. Others were placed on antibiotics for respiratory conditions, urinary tract infections, and a variety of other medical issues not usually associated with sheltering.

Federal Medical Stations deployed by the HHS Office of the Assistant Secretary for Preparedness and Response at the request of states are described as sheltering resources that "sustain from 50 to 250 stable primary or chronic care patients who require medical and nursing services [providing] low acuity care for patients with chronic illnesses whose access to care is impeded due to the disaster."[67]

Like the HHS CDC guidance, this guidance is contrary to the *Olmstead* integration mandate. Language used in this guidance is out of sync with the HHS Office for Civil Rights statement that generally does not support segregation of people with disabilities that are in shelters.

Despite guidance from DOJ, CRCL and FEMA, disaster survivors with disabilities are often forced to be separated from family, friends, and neighbors in shelters designated solely for people with disabilities and their assistants. These 'medical special needs' shelters,' 'medical friendly' shelters, 'special needs' shelters, 'Federal Medical Stations,' and other similarly described facilities are the only type of emergency sheltering provided for many people with disabilities living in the community who do not have the need to be served in a nursing home or hospital. The use of these facilities has been prevalent in many of the recent disasters requiring evacuation of disaster-impacted communities.

Shelters designated only for disaster survivors with disabilities have operated in Florida, Louisiana, South Carolina, North Carolina, Virginia, and other states with federal disaster declarations over the past three years. Most recently, the conditions in these segregated shelters have been described as "less than optimal."

As Senator Lowell Weicker, the original sponsor of the ADA, stated during consideration of the ADA's passage: "Separate is not equal. It was not for blacks; it is not for the disabled." Senator Edward Kennedy likened segregation of persons with disabilities to an "American apartheid," and Congress repeatedly invoked Brown v. Board of Education as a basis for prohibiting segregation based upon disability."[68]' Evacuation Centers,' including those funded with FEMA P-361 grant funds, are, despite the grant instructions, repeatedly described by local and state government as "different than shelters" and "not required to provide disability accommodations," such as accessible bathrooms, personal assistance, interpreters, accessible cots, and other reasonable accommodations.[69] A document written in response to Hurricane Lane in Hawaii about evacuation shelters indicated, under a column labeled "Access and Functional Needs," that "Lack of trained staff and backup power is expected." (See Appendix 1.)

Under the Rehabilitation Act, "entities selected to receive a grant, cooperative agreement, or other award of federal financial assistance from the U.S. Department of Homeland Security (DHS) or one of its Components, including State Administering Agencies must comply with civil rights obligations . . . Sub recipients have the same obligations as their primary recipient to comply with applicable civil rights requirements and should follow their primary recipient's procedures regarding compliance with civil rights obligations."[70] However, time and again, people with disabilities are not being accommodated "in the most integrated setting appropriate to their needs, which is typically a mass care shelter." [71]

Stakeholders report civil rights violations that were due to failure to provide necessary guidance, training and technical assistance to state and local government; failure to monitor compliance; and failure to enforce civil rights laws that apply before, during and after disasters. Contributing to these failures is contradictory information about the requirements for sheltering people with disabilities in emergencies and disasters.

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

If federal responsibility is not already settled, ownership must be immediately assigned, and compliance enforced by the responsible federal agencies. If ownership has been determined, the responsible federal agency has failed to act, and this failure must be immediately addressed, and compliance enforced by the highest level of authority necessary.

"Special needs" shelters are medically oriented facilities that lead to medically oriented solutions. They don't provide adequate care and they are often

very short-term options with heavy pressure to close quickly because of their high expense, a circumstance that may lead to immediate institutionalization. For example, in the 2006 flooding in Louisiana, the state opened a special needs shelter at Louisiana State University. The Department of Health and Human Services was requested to deploy Disaster Medical Assistance Teams to support the operation of this Federal Medical Station. It was reported on daily FEMA community stakeholder calls that this was at a cost of $500,000 each day. It was also reported that the University had established an end date for the use of their facility to accommodate a sports event. Cost and availability ultimately drove the decision to move approximately 100 people to institutions. Despite the fact that the Red Cross was actively working with the state to meet the sheltering needs of most of the special needs shelter residents in their general population shelters nearby, their offer was refused.

Recommendation: NCD recommends that DOJ issue a fact sheet defining monitoring and enforcement obligations in order to ensure compliance with civil rights requirements in the placement, tracking and use of federal funds associated with emergency and disaster sheltering of people with disabilities.

The double impact of non-compliance and inconsistent guidelines has resulted in the denial of equal access to emergency programs and services for disaster-impacted individuals with disabilities, violating their civil rights and leading to unnecessary institutionalization.

Transitioning out of shelters

Lack of housing, including affordable and accessible housing, at the time that shelters close is a huge barrier, threatening the independence of people with disabilities and frequently leading to institutionalization.[72] A man with a disability refused to leave a shelter in Louisiana during the 2016 flooding. He was threatened with institutionalization until an advocate intervened. Once he could explain his reason for refusing to leave, it was learned that he had already secured housing several hours away, and he had arranged to purchase a car to drive there as soon as $5,000 approved by FEMA was deposited in his account so he could complete the purchase.

Difficulties transitioning from shelters to the community are exacerbated when people are moved to distant shelters or moved multiple times, often without notification of loved ones. Following Hurricane Michael, a stakeholder reported that people were transported from a 'special needs' shelter in Panama City, Florida, to an unknown location that was a seven-hour drive from the original shelter. Similar instances were reported during other disasters, including the Jefferson County, Texas, evacuation reported by CNN and previously described.

Repeatedly, people with disabilities who were described as "pre-disaster homeless" are the last residents of shelters. In many communities, the previously existing homeless services have been interrupted or eliminated. As a result, people are institutionalized either because they have nowhere to go or because health deterioration due to lack of health maintenance requires medical care.

Recommendation: NCD recommends that FEMA immediately fund a national initiative to identify, catalog, track real time availability of, and reserve all accessible hotel and motel rooms for, use throughout the FEMA Transitional Sheltering Assistance (TSA) program. This must include identification of guest rooms with roll-in showers, accessible kitchens, and accommodations for people with vision and hearing disabilities and chemical sensitivities.

Recommendation: NCD recommends that Independent Living Center staff, other affordable and accessible housing experts and experts on disability and community living, be funded by FEMA, HHS (ACF and ACL) and HUD to provide individual and household disaster case management focused on the transition and permanent housing and community living needs of disaster-impacted people with disabilities. Disaster case management for housing, community living, and related needs must begin no later than one week after an Individual Assistance Disaster Declaration is declared by the president. All short-term and long-term disaster case management must be delivered by qualified disability culturally competent community living experts and continue until each disaster survivor with a disability is housed in permanent housing that is in the most integrated setting appropriate to their needs, with all necessary supports and services in place.

Housing shortages

The Disaster Recovery Housing Coalition, led by the National Low Income Housing Coalition, called on Congress to "make certain that federal disaster recovery resources reach all impacted households, including those with the lowest incomes who are often the hardest-hit by disasters and have the fewest resources to recover afterwards."[73]

A DHS listening session participant shared the following anecdote:

A family of six, including three children with disabilities, was living in HUD housing that was deemed substandard and condemned by HUD. They stayed in the home because they had nowhere else to go. During the cold weather of December, the home burned down. The family was living in their car as of February 2018. The children with disabilities, like all children with disabilities experiencing homelessness, were at increased risk of institutionalization.

As of late February 2018, six months after Hurricane Harvey, 27,000 people in Texas were without permanent housing solutions. Two months later, the numbers had not diminished markedly. One year after the hurricane, the disaster hotline continued to receive daily calls from panicked survivors desperate for housing, and often reporting that they are within hours of homelessness.

Admission to an institution during and after a disaster may result in long-term institutionalization.

This may occur when loved ones, advocates, and allies lose track of where the person with a disability was ultimately placed. This is particularly problematic for people who don't communicate verbally and/or have intellectual disabilities. Public health professionals underestimate how difficult it is for disaster survivors with disabilities to move back to the community after institutionalization.

The shortage of affordable accessible housing across the country is exacerbated following disasters. This contributes to the institutionalization of people with disabilities. Numerous key informants reported that shelter operators and disaster recovery workers were more likely to refer people with disabilities to nursing homes and other institutions when it was perceived that this was the only alternative to homelessness. In other words, if they perceived the choices as between sending a person with a disability to a nursing home or to a homeless shelter, they valued institutionalization as a better option. This choice is made easier by the CMS waiver to expedite nursing home placement.

Institutionalization of people with disabilities due to lack of affordable, accessible and conventional housing is a public policy failure that extends beyond failing to provide equal access to disaster-related programs and services. Even if people with disabilities were provided equal access to programs and services, institutionalization would still be an issue due to the shortage of affordable, accessible and conventional housing.

The goal of disaster recovery is always to reestablish the full function of every community impacted by disasters. Permanent housing is a fundamental element of recovery. For people with disabilities and their families, accessible, affordable housing located in proximity to goods, systems, services, and networks is vital to their community participation, inclusion, and independence.

Housing resources are scarce in every community before disaster strikes. The issue is exacerbated when housing is damaged or destroyed, causing disproportionate upheaval, relocation, and service disruption which may result in institutionalization of people with disabilities. And yet, programs and services to address the consequences of disasters are routinely overlooked in planning.

Guardianship and abandonment

Legal mechanisms by which people with disabilities may be institutionalized during and after disasters include civil commitment and guardianship/conservatorship state statutes.

People were civilly committed or threatened with such because they refused to comply with evacuation orders. Most notoriously this happened in Florida where people were committed under what is known in Florida as the Baker Act (Florida Statute 394.451-394.47891). On March 20, 2019 WJCT Public Media reported that Bay County Florida School District Superintendent Bill Husfelt told the Florida State Board of Education that "before the storm, there were 738 homeless students in the district. Now, there are more than 4,800." "There have been 700 Community of Care referrals to mental health agencies. We've had 70 baker acts since we've reopened, 35 since Feb. 25th, 62 since Christmas Break." He added that "One of the youngest students to be involuntarily committed under the state's Baker Act was 6-years-old." [74]

Recommendation: NCD recommends that HUD establish metrics and measure the nationwide availability of the ready supply of accessible, adaptable, affordable, and disaster-resistant permanent and temporary housing.

Recommendation: NCD recommends that FEMA and HUD create a system 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 system must measure and report compliance with accessibility standards.

Recommendation: NCD recommends that HUD compiles these and their other annually reported federally funded housing accessibility data, with an intent to provide measurable increases in the federal investments in accessible housing.

Civil commitment, guardianship and conservatorship was used in other disaster-impacted states as well, to facilitate institutionalization during and after disasters. According to Disability Rights Texas, hospitals attempted to place people with disabilities under temporary guardianship in order to force placement in a nursing facility against the person's wishes; the legal mechanism was Chapter 1251 of the Texas Estates Code. These actions were prevented by Disability Rights Texas. Even with laws in place to protect rights; however, waivers have routinely been granted by the Centers for Medicare and Medicaid Services (as discussed earlier), forcing people into nursing homes in other states for the convenience of hospitals, with no consideration of the needs or rights of the person and without guardianship or conservatorship actions.

Because public health, medical, and local emergency officials may regard people with disabilities, including older adults, from a perspective of paternalism, they may decide that conditions in a nursing home are superior and the environment safer than the person's home. This is particularly true when the person lives in low-income housing or a mobile home. Key informants report that public health, medical, and local emergency officials sometimes see the person with a disability as being "better off" in a nursing home.

During disasters, it is often reported that people with disabilities are abandoned at emergency rooms and nursing homes. These people are abandoned by family and paid caregivers who may take this drastic step because of inadequate planning and limited resources or simply an abdication of responsibility. Other causes may be a basic lack of equal access to services for the person with a disability, and the inability of family members and paid caregivers to meet the needs outside of the home.

Abandonment may be a hostile or compassionate act, but the result—institutionalization—is usually the same. Whatever the motive, failure to plan for the needs of people with disabilities in disasters forces a broken system to provide services, which will almost always result in institutionalization.

Recommendation: NCD recommends that DOJ and HHS monitor and enforce the ADA *Olmstead* integration mandate and Rehabilitation Act obligation to use federal funds in compliance with requirements to serve people in the most integrated setting appropriate to their needs inclusive of disaster-impacted people with disabilities who have been subjected to civil commitment or have guardians/conservators.

Other instances of abandonment were reported on stakeholder calls and by key informants. One key informant described disaster-impacted people, including people with disabilities, being dropped off by the National Guard at a gas station in North Carolina at night. When the key informant discovered the abandoned group, the evacuees said they thought they were being brought to a shelter, but the shelter had either been closed or located elsewhere and the National Guard told them someone else would come to pick them up. No one ever came.

In Florida, during Hurricane Michael, rescuers found a group of over 70 people with disabilities and older adults at a hotel in the Panama City area, many of whom had been abandoned at the hotel. Hotel staff were doing what they could to help, but several people were in urgent need of medical assistance. Some needed oxygen, others had complex needs that hotel staff were ill-equipped to meet. The rescuers believed that most of these individuals came from a long-term care facility, but others had been dropped off there, as well. Ultimately, rescuers were able to help some to reunite with family, but others were institutionalized. One young man, who has quadriplegia, was able to leave with his family, but his custom-power wheelchair was left behind on an upper floor of the hotel.

Recommendation: NCD recommends that the federal entity (typically FEMA and DHS) providing funds that are ultimately received by local emergency management requires participation of local staff in training and demonstration of the scope of their obligations under the Rehabilitation Act regarding people with disabilities who have been abandoned during evacuation, sheltering, and transition to long-term housing.

Recommendation: NCD recommends that DOJ monitor and enforce civil rights compliance throughout all phases of disaster response to prevent abandonment on the part of government entities, such as National Guard and other recipients and subrecipients of federal financial assistance.

Chapter 4: Practices to Curtail and Prevent Institutionalization

In this chapter, practices thought to curtail and prevent institutionalization of people with disabilities during and after disasters is examined. The efficacy of these practices informed the recommendations listed in Chapter 5.

Promising practices to curtail institutionalization during and after disasters

Promising practices include national and local stakeholder calls led by people with disabilities that provide a forum during which stakeholders—including staff members from Centers for Independent Living, mayor's offices on disability issues, emergency management offices, Red Cross, state/territorial and federal agency departments, protection and advocacy systems, and other key entities—shared anticipated and existing barriers to equal access to disaster-related programs and services, as well as resources. The calls were a daily resource for solving complex problems, such as situations involving the potential or actual institutionalization of disaster-impacted people with disabilities of all ages. These calls were a consistent source of documented information that brought to light patterns of circumstances leading to institutionalization.

Another good practice is the disaster hotline established by the Partnership for Inclusive Disaster Strategies, a disability community-led initiative staffed by experts in community living. Before, during and after disasters, disaster hotline staff facilitated rescue, provided local resource referrals, and, in partnership with Trach Mommas of Louisiana and the Pass It on Center, identified, matched and delivered durable medical equipment, disability supplies, and assistive devices to people whose disability-related items were lost, damaged, or destroyed. This assistance prevented institutionalization.

The leadership of local disability organizations … were always the most knowledgeable sources of immediate local solutions preventing institutionalization.

The leadership of local disability organizations is critical to meeting the needs of people in disaster-impacted communities. When Centers for Independent Living, University Centers for Excellence in Developmental Disabilities, developmental disabilities councils, Protection and Advocacy systems, and other local disability groups were functional, they were always the most knowledgeable sources of immediate local solutions preventing institutionalization.

However, their efforts were continually suppressed by numerous factors, including exclusion from disaster funds and resources; power plays by the traditional disaster relief leadership organizations; actions of medical model outsiders; charity model activity; media coverage that embraced stereotypes; and volunteerism in place of disability experts qualified to assure that the civil rights of people with disabilities are upheld at all times throughout the disaster cycle.

Local disability organizations are also key resources for helping disaster survivors apply for FEMA and other government and non-government disaster relief programs and services. This assistance is especially important because of significant problems navigating the complexities of these eligibility processes. When disaster survivors with disabilities receive assistance, they are far more likely to remain in the community.

According to FEMA, there are ongoing attempts to improve its registration process, which includes help desks for call centers and website and mobile app access. There is currently a work group tasked with improving question 24 on the Individual Assistance registration form. Due to aging IT infrastructure and required governmental processes to amend, the registration process, including reasonable accommodations, remains unchanged.

During the response to Hurricane Florence, Centers for Independent Living in both North and South Carolina took a lead in preventing

institutionalization despite very formidable and conflicting directives from federal and state government.

Recommendation: FEMA should explore ways to expeditiously modify its Individual Assistance registration process to curtail the incidence of institutionalization of individuals with disabilities.

One of many examples of good practice was demonstrated by the ADA Center for Independent Living in Raleigh, North Carolina, which embedded their staff in a "special medical needs shelter." This shelter was established in a closed state psychiatric hospital. The Center recognized quickly that the people sent to this shelter were being considered for institutionalization, and that there was no one responsible for discharge planning or tracking from one setting to another. They provided significant guidance and technical assistance that ultimately prevented all but six of over one hundred evacuees from being institutionalized.

Strong ties to communities are invaluable. Neighbors assisted people with disabilities in obtaining food, waiting in line, and other ways during and after disasters. The more connected with the community a person with a disability is the more likely they will be assisted by friends and neighbors. When a person with a disability is isolated from the community, they are unable to make friendships and forge relationships with neighbors and other community members who could assist them. A neighbor is more likely to approach and help someone they know. Strong community connections help prevent institutionalization.

Strong community connections help prevent institutionalization.

Recommendation: NCD recommends that DHS/FEMA and HHS/ACL provide grant funds to support Independent Living Centers in their support of disaster-impacted people with disabilities in their community. This support incorporates all core services, including their obligations for preventing and diverting institutionalization of disaster-impacted people throughout disaster response and recovery.

Teams of disability experts were deployed to Puerto Rico and the U.S. Virgin Islands. These teams worked on the ground to supplement the work of local disability organizations who were devastated by Hurricane Maria, and to prevent both institutionalization and loss of life. Portlight also supported the development of a network of disability organizations in Puerto Rico which has become a formidable force for change as the Island recovers.

Although mainstream funding has continued to elude many disability organizations, these organizations continue to address both current and future readiness and disaster resilience, both of which are imperatives to preventing institutionalization.

Previous efforts to place qualified disability

experts into all areas of federal preparedness, response, and recovery initiatives have been relegated to the workloads of unqualified generalists.

Recommendation: NCD recommends that federal agencies with disaster response and recovery responsibilities immediately place disability experts identified from the National Qualification System on meeting the civil rights of disaster-impacted people with disabilities to prevent institutionalization in the field in support of all FEMA Joint Field Offices and Area Field Offices.

Individualized accommodations as an approach to curtailing institutionalization during and after disasters

As stated above, accommodations that provide equal access to disaster-related programs and services are required by federal law. The need for disaster-related accommodations is always foreseeable. However, providing them to prevent institutionalization requires both anticipating and solving problems. Effective problem-solving also requires a commitment to serving people with disabilities in the most integrated setting appropriate to their needs under all circumstances.

Even though failure to plan for providing individualized accommodations is not a valid reason for choosing institutionalization, it is frequently cited as a necessary solution "in light of the disaster." Institutionalization is neither an alternative of first resort nor last resort. Institutionalization should not be an acceptable option for disaster-impacted people with disabilities.

Even though failure to plan for providing individualized accommodations is not a valid reason for choosing institutionalization, it is frequently cited as a necessary solution "in light of the disaster."

Providing accommodations quickly and creatively can prevent institutionalization and allow disaster-impacted people to successfully remain in the community. Some examples of accommodations that can prevent institutionalization in shelters and throughout disaster service delivery include:

- Alternative environments, such as quiet and low stimulation space, to accommodate people who are neurodivergent; those with mental health needs; and others who can best maintain their health, safety, and independence with the provision of these accommodations.
- Accessible toilets and showers wherever disaster survivors may need them.
- Provision of durable medical equipment, assistive devices, disability supplies, and other resources vital to health maintenance and independence. These may be needed as replacements for lost, damaged, or destroyed items, or they may be necessary for functioning in an environment different from the person's home and usual

environment. (Many people can navigate short distances in familiar settings but would need a mobility device to navigate the distances between sleeping, bathroom, meal, and other key locations in a shelter or at a Disaster Recovery Center.)

- Provision of sign language interpreters; open captioning; batteries for hearing aids and cochlear implants; tactile wayfinding; use of plain language; and pictograms and actionable information in alternate formats, including formats that are accessible to people who are Deafblind, people with intellectual disabilities, and people with low literacy. Alternatives for people with chemical sensitivities and allergies should be available as well.
- Training of first responders, shelter, and disaster relief workers to problem-solve rather than medicalize disability.

Strategies for strengthening promising practices

Outcome-driven and evidence-based practices are an imperative for meeting the disaster-related needs of people with disabilities; in addition, they are critical to achieving and maintaining community resilience for all.

Promising practices must be acquired, tested, and replicated before disasters strike. Exercises must pose real challenges that test prevention of institutionalization. During disasters, the effectiveness of these practices must be measured, and continual improvement strategies employed. After Action reporting should not be an opportunity to absolve failure, but rather an opportunity for continual improvement by means of careful examination and development of updated goals, objectives, priorities, processes, and procedures.

> **Recommendation:** NCD recommends that HHS establish a process for states and territories for loaning and replacing durable medical equipment, consumable medical supplies, assistive technology, disability services and supports, as 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.

Strategies to strengthen implementation of good practices include the following recommendations:

> **Recommendation:** NCD recommends that Congress enact legislation by expansion of the previously introduced 2018 READI for Disasters Act, the 2019 REAADI in Disasters Act.

The 2019 REAADI for Disasters Act will:

- Establish a research center to be defined in legislation, such as in the READI in Disasters Act to conduct research to determine recommended practices for including people with disabilities and older adults in planning

during and following disasters. The research should include its focus on but not limited to:

- Ensuring that universal design is 'baked into' all aspects of preparedness, response, and recovery, not tangentially considered as afterthought or annex.
- Making certain that people with disabilities are 'at the table' and that their role is real, not tokenized, using a 'nothing about us, without us' philosophy.
- Designating qualified people with disabilities to serve in leadership roles.
- Ensuring that disability organizations are key stakeholders throughout preparedness, planning, response, recovery, mitigation, and community resilience initiatives.
- Compensating disability organizations commensurate with prevailing pay scales.

- 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 and identify strategies for reducing deaths, injuries, and losses to those groups as a result of disasters.
- Establish a National Commission on Disability Rights 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 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.

Chapter 5: Recommendations

Without immediate and aggressive policy and practice changes, the continued institutionalization of disaster-impacted people with disabilities is inevitable.

NCD's recommendations are urgent. This is due to continued devastation from the number and intensity of disasters, and their disproportionate impact on children and adults with disabilities and older adults.

The following recommendations provide a roadmap toward outcomes that preserve the freedom of the 61 million people with disabilities whose right to equal access before, during and after disasters will be threatened as soon as the next disaster strikes.

Recommendations

1. NCD recommends passage of legislation such as the READI in Disasters Act and the Disaster Relief Medicaid Act should be passed and enacted immediately to address gaps in meeting civil rights obligations to people with disabilities impacted by disasters.
2. NCD recommends that Congress require CMS to establish a process for Medicaid portability among states and territories during disasters to ensure uninterrupted health maintenance and medical care in the least restrictive environment for Medicaid recipients.
3. NCD recommends federal entities require that all recipients and subrecipients of federal funds receive training in the scope of their obligations to people with disabilities. 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.
4. NCD recommends federal entities monitor recipients and subrecipients of federal funds to ensure compliance throughout all disaster-related placement decisions by recipients and subrecipients of federal financial funds.
5. NCD recommends that the federal entity (typically FEMA and DHS) providing funds that are ultimately received by local emergency management requires participation of local staff in

Recommendations, *continued*

training and demonstration of the scope of their obligations under the Rehabilitation Act regarding people with disabilities who have been abandoned during evacuation, sheltering, and transition to long-term housing.

6. NCD recommends that federal agencies responsible for emergency preparedness, community resilience, and disaster-related services, programs, supports, or activities must engage with national, state, and local coalitions of disability-led organizations and stakeholders. These federal agencies include but are not limited to: DHS, FEMA, CRCL, HHS, ASPR, ACL, ACF, ILA, CDC, HUD, DOT, DOJ, DRS, ED, OSERS, DOL, ODEP, DOD, Veterans Affairs, U.S. Access Board.
7. NCD recommends that FEMA 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.
8. NCD recommends that ED takes immediate action to ensure that disaster-impacted students with disabilities are not excluded from 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.
9. NCD recommends that FEMA's ESFLG establish 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 evacuation, temporary housing, and disaster recovery.
10. NCD recommends that Congress amend the Stafford Act to require HHS to have active engagement with disability organizations with specific expertise and involvement in national disability inclusive emergency management policy and practice. The provision should be similar to those in PKEMRA requiring community engagement by FEMA.
11. NCD recommends that Congress 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

Recommendations, *continued*

experiencing poverty; people with disabilities experiencing homelessness; women with disabilities; people of color with disabilities; and members of the LGBTQ community with disabilities.

12. NCD recommends that DOJ and HHS monitor and enforce the obligation under both the ADA and the Rehabilitation Act to serve people in the most integrated setting appropriate to their needs.
13. NCD recommends that the FCC 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.
14. Because special needs registries are at best ineffective and at worst misused to steer people with disabilities into institutions, NCD recommends that no federal funds, including but not limited to federal funds from the U.S. Department of Homeland Security and the U.S. Department of Health and Human Services, be used in development, deployment, and maintenance of emergency 'special needs' registries exclusively created for people with disabilities.
15. NCD recommends that the Federal Mass Evacuation Plan, 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.
16. NCD recommends that HHS (CMS) in collaboration with all other federal entities with admission and monitoring or funding and reimbursement obligations maintains responsibility for ensuring that all admissions to hospitals and long-term care facilities during and after disasters are monitored 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.

Recommendations, *continued*

17. NCD recommends that DOJ and other federal entities with enforcement authority:
    a. 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.
    b. Monitor and enforce civil rights compliance with Titles II and III of the ADA regarding sheltering.
18. NCD recommends that DOJ and HUD 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 be expected in both transient and long-term disaster shelters.
19. NCD recommends that Congress enact legislation by expansion of the previously introduced 2018 REAADI for Disasters Act, the 2019 READI in Disasters Act to:
    a. Establish a research center to be defined in legislation, such as the READI in Disasters Act to conduct research to determine recommended practices for including people with disabilities and older adults in planning during and following disasters.
    b. 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 and identify strategies for reducing deaths, injuries, and losses to those groups as a result of disasters.
    c. Establish a National Commission on Disability Rights 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.
    d. Establish 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.
    e. Require DOJ to create an oversight committee that will review all ADA settlement

Recommendations, *continued*

agreements related to disaster-response activities for the years 2005 to 2017.

20. NCD recommends that Congress request a report from GAO to investigate whether past federal disaster funds have been used to ensure accessibility to emergency programs and services.
21. NCD recommends that DOJ provide pointed guidance to sister federal agencies to address the issue of outdated regulations that conflict with the *Olmstead* integration mandate.
22. NCD recommends that Congress require agencies to document the transfer of people with disabilities from the community, emergency shelters, and other general population settings to hospitals, nursing homes, assisted living, long-term care, rehabilitation, psychiatric institutions, hospice, and other medical facilities. Documentation should include any movement among any of these community, institutional, and medical facilities. The legislation should include specific mandates for CMS to take to ensure that each person (inclusive of people not receiving Medicare or Medicaid services) is provided with all of the services and supports required for successful return to the most integrated setting appropriate to their needs.
23. NCD recommends that Congress requires that HHS establishes a data collection system and that data collection begins immediately after the next federally declared disaster. The system must identify every impacted individual who was moved to an institutional setting and quantify movement and displacement of all impacted people in the aggregate.
24. NCD recommends that HHS provides funding to 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.
25. NCD recommends that DOJ 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.
26. NCD recommends that DOJ issue a fact sheet that defines monitoring and enforcement obligations in order to ensure compliance with civil rights requirements in the placement,

Recommendations, *continued*

as well as to track and use of federal funds associated with emergency and disaster sheltering of people with disabilities.

27. NCD recommends that Congress appropriate funds for FEMA to immediately commence a national initiative to identify, catalog, track real time availability of, and reserve all accessible hotel and motel rooms for, use throughout the FEMA Transitional Sheltering Assistance (TSA) program. This must include: Identification of guest rooms with roll-in showers, accessible kitchens, and accommodations for people with vision and hearing disabilities and chemical sensitivities.
28. NCD recommends that Independent Living Center staff and other affordable and accessible housing experts be funded by FEMA, HHS (ACF and ACL) and HUD to provide individual and household disaster case management focused on the transition and permanent housing needs of disaster-impacted people with disabilities.
29. NCD recommends that Congress appropriate funds for FEMA, HHS (ACF and ACL) and HUD to fund Independent Living Center staff 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.
30. NCD recommends that HUD establish metrics and measure the nationwide availability of the ready supply of accessible, adaptable, affordable, and disaster-resistant permanent and temporary housing.
31. NCD recommends that FEMA and HUD create a system 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 system must measure and report compliance with accessibility standards.
32. NCD recommends that DOJ 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.

Recommendations, *continued*

c. Ensure compliance with Titles II and III of the ADA pertaining to sheltering.

33. NCD recommends that FEMA explore ways to modify their Individual Assistance registration process expeditiously to curtail the incidence of institutionalization of individuals with disabilities.

34. NCD recommends that federal agencies with disaster response and recovery responsibilities, specifically 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.

35. NCD recommends that the member agencies of the ICC should place disability experts in the field and in support of 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 insure adequate expertise in guiding compliance with the civil rights of disaster-impacted people with disabilities to prevent institutionalization.

36. NCD recommends that HHS establish a process for states and territories for loaning and replacing durable medical equipment, consumable medical supplies, assistive technology, and disability services and supports–as 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.

37. NCD recommends that the Veterans Administration and HHS collaborate 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.

Appendix 1

(American Red Cross Logo)

DR 694-18 Hurricane Lane, HI

Red Cross role in Hurricane Evacuation Centers and Shelters

August 23, 2018

DR 694-18 Hurricane Lane, HI

Red Cross role in Hurricane Evacuation Centers and Shelters

Summary

The Hawaii State Emergency Operations Plan, Hurricane Evacuation Shelters Planning and Operations Guidelines December 2017 document clarifies the Red Cross and local government role during and after a major hurricane.

National guidance that is used in most CONUS evacuations that is NOT being used is identified in *italic text below.*

State ESF 6 Agencies:

Primary: Dept. of Defense: HI-EMA; Dept of Human Services; Red Cross

Support: Dept. of Accounting & General Services, Office of Elections; Dept. of Agriculture; Dept. of Attorney General; Dept. of Business, Economic Dev. & Tourism; Hawaii Tourism Authority; Dept. of Education; Dept. of Hawaii Home Lands; Dept. of Health; Dept. of Human Service; Public Housing Authority; Dept. of Labor and Industrial Relations; University of Hawaii; General Contractors Assn.; HI Assn. of Animal Welfare Agencies; HI Food Industry Assn.; HI Veterinary Medical Assn.; State VOAD.

Evacuation Centers

Activity	Local Government Role	Red Cross Role
Public messaging on evacuation decision	Communities are encouraged to shelter in place at home, work, or with friends and family and only take refuge in a shelter if their primary home or other option is not safe. Messaging emphasizes that no services, food or supplies will be provided.	None stated. Typically, Red Cross expects evacuation orders along coastal areas to result in large inland evacuation shelter populations.
Sheltering operations	Counties are the designated operating agency on shelters.	Shelters are described as "Hurricane Evacuation Centers" to avoid confusion with typical sheltering.
Supplies and Services	No supplies or services are provided, including cots, blankets, or food. Residents are expected to bring their own food, water, and medicine.	None stated. During East Coast evacuation sheltering, 10 % supply of cots, food, and limited medical services are planned.

Activity	Local Government Role	Red Cross Role
Staffing	Minimal staffing, expected below national recommended standards.	Red Cross staff are asked to augment county staff (3-5 workers), particularly where there are staffing shortages. Also, shelter managers and workers are trained by Red Cross prior to an event from county EMA and Dept. of Education staff. If Red Cross staff are supporting a government shelter, the expectation is that a government shelter manager/lead is onsite. This may not be the case, which could cause some confusion.
Space	State guidance is to provide 10-square feet per person.	Red Cross typically uses 20-square feet per person.
Facility selection	Counties are encouraged to use schools. HI-EMA maintains the list of sights and has invested in hardening some identified facilities. Most will not withstand a major hurricane, and most have not had a full structural assessment.	

Activity	Local Government Role	Red Cross Role
Household pets	Not permitted in human shelters, Hurricane Evacuation Pet Shelters are operated by counties, possibly co-located at schools.	
Service animals	Permitted.	
Dormitory space	Dormitories are encouraged to be housed in small classrooms spread across multiple buildings rather than gymnasiums due to the perceived lack of structural integrity of long-span roofs. This is expected to cause difficulty in site supervision, protection of equipment, communication among team members, access to restrooms, etc.	Red Cross workers are likely to be recruited to manage dormitory areas. This is a county decision. Most shelters in NSS inventory and most Red Cross training assumes a gymnasium or large congregate areas will be the shelter.
Food	Shelter residents are expected to bring a 14-day food supply with them. Up to 50% of the shelter population are expected to do so. Salvation Army is the lead agency for feeding.	Red Cross is asked to provide food in many CONUS. evacuations. This is not expected here.

Activity	Local Government Role	Red Cross Role
Communications	Extremely limited, expected to fail.	Amateur radio operators may be available to support Red Cross communication with staff.
Health and Medical	Counties are encouraged to assign at least one healthcare staff member on site, with a basic first aid kit only.	
Access and Functional Needs	Lack of trained staff and backup power is expected.	
Pre-disaster homeless	Shelter population is expected to make up a significant percentage of the population. They are unlikely to have a 14-day food supply and have high medical and mental health needs. No significant services are planned during evacuations.	
Visitors and Tourists	Appx. 15% of state population are visitors, up to 30% in some counties. Visitors are not expected to bring their 14-day food supply.	
Reporting	Counties are expected to report to State EOC when an evacuation shelter is open.	NSS usage at state and county levels is expected.

Activity	Local Government Role	Red Cross Role
Security	Counties are responsible for managing security at shelters.	

Post Impact Shelters

Activity	Local Government Role	Red Cross Role
Facility selection	Schools are discouraged, and are likely to close, consolidating shelters to other public and private locations after the storm has past.	
Sheltering operations	Counties are expected to continue to be the operator supported by Red Cross.	Typically, Red Cross expects to open Red Cross operated shelters after impact. This does not appear to be in the plan.
Food		Red Cross is expected to have an increased role, not currently defined.

Appendix 2

NCD Letter to CDC regarding NCD research into institutionalization of people with disabilities during and after disasters:

November 28, 2018
Robert R. Redfield, MD
Director
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30329

Dear Dr. Redfield:

The National Council on Disability (NCD) entered into Cooperative Agreement # 18-03 on July 16, 2018 with the Partnership for Inclusive Disaster Strategies (Partnership) —a national coalition of individuals and organizations whose mission is equal access and full inclusion for the whole community before, during and after disasters—to research and complete a report evaluating institutionalization of persons with disabilities during and after disasters. When complete, it will be provided to the President, Congress, and federal agencies potentially impacted by NCD's recommendations.

I am writing as follow-up to the request by Partnership for the CDC to provide data and information regarding admissions from Federal medical stations to hospitals, nursing homes, assisted living facilities, skilled nursing facilities, rehabilitation facilities, hospices, and other long-term care facilities during and after the 2017 and 2018 disasters, beginning on August 25, 2017and continuing through the present time. Such data is needed to fulfill the responsibilities outlined in the cooperative agreement.

NCD is an independent federal agency, and is statutorily authorized to "review and evaluate on a continuing basis—policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies … in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of

individuals with disabilities." 29 U.S.C. § 781(a)(5). NCD is also required to "assess the extent to which such policies, programs, practices, and procedures facilitate or impede the promotion of the policies" that "guarantee equal opportunity for all individuals with disabilities … and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society." Id. § 781(a)(6) (referencing 29 U.S.C. § 780(a)(2)).

The cooperative agreement between NCD and Partnership states, in relevant part, that:

"This cooperative agreement is necessary to the discharge of NCD's duty to review and evaluate on a continuing basis new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including … Access to personal assistance … Access to health care, and policies that operate as disincentives for individuals to seek and retain employment." 29 U.S.C. § 781(a)(10). Under this cooperative agreement, the Parties will produce a research product on the institutionalization of people with disabilities before during and after disasters. As required by the Federal Grant and Cooperative Agreement Act, "substantial involvement is expected between the executive agency and the … Recipient when carrying out the activity contemplated in the agreement." 31 U.S.C. § 6305(2).

Pursuant to the above, Partnership will need the requested data provided to develop NCD's report in a timely manner to ensure CDC's data and information is included in the report. I appreciate your prompt consideration and cooperation in assisting NCD with the data collection previously requested. You may provide the data directly to Amy Nicholas, Attorney Advisor, National Council on Disability at anicholas@NCD.gov. Ms. Nicholas can also be reached at 202-272-2008.

Sincerely,
Neil Romano
Chairman
cc: Partnership for Inclusive Disaster Strategies

Appendix 3

NCD Letter to CMS regarding NCD research into institutionalization of people with disabilities during and after disasters:

November 28, 2018
Seema Verma
Administrator
Centers for Medicare and Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244

Dear Administrator Verma:

The National Council on Disability (NCD) entered into Cooperative Agreement # 18-03 on July 16, 2018 with the Partnership for Inclusive Disaster Strategies (Partnership) —a national coalition of individuals and organizations whose mission is equal access and full inclusion for the whole community before, during and after disasters—to research and complete a report evaluating institutionalization of people with disabilities before, during, and after disasters. When complete, it will be provided to the President, Congress, and federal agencies potentially impacted by NCD's recommendations.

I am writing as follow-up to the request by Partnership for CMS to provide data regarding disaster-related admissions to nursing homes, assisted living facilities, skilled nursing facilities and other long-term care facilities during and after the 2017 and 2018 disasters, beginning on August 25, 2017, and continuing through present time. Such data is needed to fulfill the responsibilities outlined in the cooperative agreement.

NCD is an independent federal agency, and is statutorily authorized to "review and evaluate on a continuing basis—policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies … in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of

individuals with disabilities." 29 U.S.C. § 781(a)(5). NCD is also required to "assess the extent to which such policies, programs, practices, and procedures facilitate or impede the promotion of the policies" that "guarantee equal opportunity for all individuals with disabilities … and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society." Id. § 781(a)(6) (referencing 29 U.S.C. § 780(a)(2)).

The cooperative agreement between NCD and Partnership states, in relevant part, that:
"This cooperative agreement is necessary to the discharge of NCD's duty to "review and evaluate on a continuing basis new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including … Access to personal assistance … Access to health care, and policies that operate as disincentives for individuals to seek and retain employment." 29 U.S.C. § 781(a)(10). Under this cooperative agreement, the Parties will produce a research product on the institutionalization of people with disabilities before, during, and after disasters. As required by the Federal Grant and Cooperative Agreement Act, "substantial involvement is expected between the executive agency and the … Recipient when carrying out the activity contemplated in the agreement." 31 U.S.C. § 6305(2).

Pursuant to the above, Partnership will need the requested questions and data provided to develop NCD's report in a timely manner to ensure Centers for Medicare and Medicaid Services data is recorded in the report. I appreciate your prompt consideration and cooperation in assisting NCD with the questions and data collection previously requested. You may provide the data directly to Amy Nicholas, Attorney Advisor, National Council on Disability. Ms. Nicholas can also be reached at (202) 272-2008.

Sincerely,
Neil Romano
Chairman
cc: Partnership for Inclusive Disaster Strategies

Appendix 4

NCD Letter to HHS regarding NCD research into institutionalization of people with disabilities during and after disasters:

November 28, 2018
Robert P. Kadlec, MD
Assistant Secretary for Preparedness and Response
U.S. Department of Health and Human Services
Office of the Assistant Secretary for Preparedness and Response
200 Independence Ave. SW.
Room 638G
Washington DC 20201

Dear Assistant Secretary Kadlec:

The National Council on Disability (NCD) entered into Cooperative Agreement # 18-03 on July 16, 2018, with the Partnership for Inclusive Disaster Strategies (Partnership) —a national coalition of individuals and organizations whose mission is equal access and full inclusion for the whole community before, during and after disasters—to research and complete a report evaluating institutionalization of people with disabilities during and after disasters. When complete, it will be provided to the President, Congress, and federal agencies potentially impacted by NCD's recommendations.

I am writing as follow-up to the request by Partnership, for the Assistant Secretary for Preparedness and Response to provide a description of its role in assessing, placing, transporting, providing funding or reimbursement to grantees and contractors and any available data and information regarding admissions to hospitals, nursing homes, assisted living facilities, skilled nursing facilities, rehabilitation facilities, hospices, and other long-term care facilities during and after the 2017 and 2018 disasters, beginning on August 25, 2017, and continuing through present time. Such data is needed in order to fulfill the responsibilities outlined in the cooperative agreement.

NCD is an independent federal agency and is statutorily authorized to "review and evaluate on a continuing basis—policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies … in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities." 29 U.S.C. § 781(a)(5). NCD is also required to "assess the extent to which such policies, programs, practices, and procedures facilitate or impede the promotion of the policies" that "guarantee equal opportunity for all individuals with disabilities … and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society." Id. § 781(a)(6) (referencing 29 U.S.C. § 780(a)(2)).

The cooperative agreement between NCD and Partnership states, in relevant part, that:

"This cooperative agreement is necessary to the discharge of NCD's duty to review and evaluate on a continuing basis new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including … Access to personal assistance … Access to health care, and policies that operate as disincentives for individuals to seek and retain employment." 29 U.S.C. § 781(a)(10). Under this cooperative agreement, the Parties will produce a research product on the institutionalization of people with disabilities before during and after disasters. As required by the Federal Grant and Cooperative Agreement Act, "substantial involvement is expected between the executive agency and the … Recipient when carrying out the activity contemplated in the agreement." 31 U.S.C. § 6305(2).

Pursuant to the above, Partnership will need the requested questions and data provided to develop NCD's report in a timely manner to ensure ASPR's roles and responsibilities are accurately recorded in the report. I appreciate your prompt consideration and cooperation in assisting NCD with the data collection previously requested. You may provide the data directly to Amy Nicholas, Attorney Advisor, National Council on Disability at anicholas@NCD.gov. Ms. Nicholas can also be reached at (202) 272-2008.

Sincerely,
Neil Romano
Chairman
cc: Partnership for Inclusive Disaster Strategies

Appendix 5

NCD Letter to FEMA regarding NCD research into institutionalization of people with disabilities during and after disasters:

November 28, 2018
William B. Brock Long
Administrator
Federal Emergency Management Agency
500 C Street SW.
Washington DC 20024

Dear Administrator Long:

The National Council on Disability (NCD) entered into Cooperative Agreement # 18-03 on July 16, 2018, with the Partnership for Inclusive Disaster Strategies (Partnership) —a national coalition of individuals and organizations whose mission is equal access and full inclusion for the whole community before, during and after disasters—to research and complete a report evaluating the institutionalization of people with disabilities during and after disasters. When complete, it will be provided to the President, Congress, and federal agencies potentially impacted by NCD's recommendations.

I am writing as follow-up to the request by Partnership for FEMA to provide a description of its role in providing funding and reimbursement to grantees and contractors and any available data and information regarding admissions to nursing homes, assisted living facilities, skilled nursing facilities and other long-term care facilities during and after the 2017 and 2018 disasters, with dates beginning August 25, 2017, through the present. Such data is needed in order to fulfill the responsibilities outlined in the cooperative agreement.

NCD is an independent federal agency and is statutorily authorized to review and evaluate on a continuing basis—policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies … in order to assess the effectiveness of

such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities." 29 U.S.C. § 781(a)(5). NCD is also required to "assess the extent to which such policies, programs, practices, and procedures facilitate or impede the promotion of the policies" that "guarantee equal opportunity for all individuals with disabilities … and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society." Id. § 781(a)(6) (referencing 29 U.S.C. § 780(a)(2)).

The cooperative agreement between NCD and Partnership states, in relevant part, that:

"This cooperative agreement is necessary to the discharge of NCD's duty to "review and evaluate on a continuing basis new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including … Access to personal assistance … Access to health care, and policies that operate as disincentives for individuals to seek and retain employment." 29 U.S.C. § 781(a)(10). Under this cooperative agreement, the Parties will produce a research product on the institutionalization of people with disabilities before during and after disasters. As required by the Federal Grant and Cooperative Agreement Act, "substantial involvement is expected between the executive agency and the … Recipient when carrying out the activity contemplated in the agreement." 31 U.S.C. § 6305(2).

Pursuant to the above, Partnership will need the requested questions and data provided to develop NCD's report in a timely manner to ensure FEMA's roles and responsibilities are accurately recorded in the report. I appreciate your prompt consideration and cooperation in assisting NCD with the questions and data collection previously requested. You may provide the data directly to Amy Nicholas, Attorney Advisor, National Council on Disability at anicholas@NCD.gov. Ms. Nicholas can also be reached at (202)-272-2008.

Sincerely,
Neil Romano
Chairman
cc: Partnership for Inclusive Disaster Strategies

Appendix 6

NCD Letter to ACL regarding NCD research into institutionalization of people with disabilities during and after disasters:

November 28, 2018
Lance Robertson
Administrator and Assistant Secretary for Aging
Administration for Community Living
330 Independence Ave. SW
Room 4760
Washington DC 20237

Dear Assistant Secretary Robertson:

The National Council on Disability (NCD) entered into Cooperative Agreement # 18-03 on July 16, 2018, with the Partnership for Inclusive Disaster Strategies (Partnership) —a national coalition of individuals and organizations whose mission is equal access and full inclusion for the whole community before, during and after disasters—to research and complete a report evaluating institutionalization of persons with disabilities during and after disasters. When complete, it will be provided to the President, Congress, and federal agencies potentially impacted by NCD's recommendations.

I am writing as follow-up to the request by Partnership for the Administration for Community Living to provide a description of its role in assessing, placing, transporting, providing funding or reimbursement to grantees and contractors and any available data and information regarding admissions to hospital, nursing homes, assisted living facilities, skilled nursing facilities, rehabilitation facilities, hospices and other long-term care facilities during and after the 2017 and 2018 disasters, beginning on August 25, 2017, and continuing through present time. Such data is needed in order to fulfill the responsibilities outlined in the cooperative agreement.

NCD is an independent federal agency and is statutorily authorized to "review and evaluate on a continuing basis—policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies … in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities." 29 U.S.C. § 781(a)(5). NCD is also required to "assess the extent to which such policies, programs, practices, and procedures facilitate or impede the promotion of the policies" that "guarantee equal opportunity for all individuals with disabilities … and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society." Id. § 781(a)(6) (referencing 29 U.S.C. § 780(a)(2)).

The cooperative agreement between NCD and Partnership states, in relevant part, that:

"This cooperative agreement is necessary to the discharge of NCD's duty to review and evaluate on a continuing basis new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including … Access to personal assistance … Access to health care, and policies that operate as disincentives for individuals to seek and retain employment." 29 U.S.C. § 781(a)(10). Under this cooperative agreement, the Parties will produce a research product on the institutionalization of people with disabilities before during and after disasters. As required by the Federal Grant and Cooperative Agreement Act, "substantial involvement is expected between the executive agency and the … Recipient when carrying out the activity contemplated in the agreement." 31 U.S.C. § 6305(2).

Pursuant to the above, Partnership will need the requested questions and data provided to develop NCD's report in a timely manner to ensure ACL's role and responsibilities are accurately recorded in the report. I appreciate your prompt consideration and cooperation in assisting NCD with the data collection previously requested. You may provide the data directly to Amy Nicholas, Attorney Advisor, National Council on Disability at anicholas@NCD.gov. Ms. Nicholas can also be reached at (202) 272-2008.

Sincerely,
Neil Romano
Chairman
cc: Partnership for Inclusive Disaster Strategies

Appendix 7

DISASTER HOUSING RECOVERY COALITION

Top Priorities for Any Disaster Recovery Package

https://nlihc.org/sites/default/files/DHRC-Priorities_Disaster-Recovery-Package.pdf

Congress is preparing its next disaster relief package for communities in North Carolina and South Carolina that were impacted by Hurricane Florence. At the same time, communities in Puerto Rico, Texas, Florida, and California are still recovering from the 2017 disasters. The Disaster Housing Recovery Coalition of 800 local, state, and national organizations urges Congress to ensure that federal disaster recovery resources reach all impacted households, including those with the lowest incomes that are often the hardest-hit by disasters and have the fewest resources to recover afterward. Below are our top priorities for Congress to include in any disaster recovery package:

PROVIDE ROBUST DISASTER RECOVERY FUNDING AND MEANINGFUL OPPORTUNITIES FOR PUBLIC INPUT.

Priority #1: Provide robust resources to allow communities devastated by the recent disasters to fully recover, including funding through HUD's Community Development Block Grant Disaster Recovery (CDBGDR) program and resources to support additional full-time disaster recovery staff at HUD. Congress should also ensure meaningful opportunities for public input by requiring a 30-day comment period on state CDBGDR action plans as well as direct grantees to establish an ongoing process for public input as rebuilding programs and projects progress to ensure community needs are being met.

PROVIDE HOUSING ASSISTANCE FOR PEOPLE WITH THE GREATEST NEEDS.

One of the top priorities after a disaster is ensuring that survivors have a stable, affordable place to call home while they get back on their feet. Under the Disaster Housing Assistance Program (DHAP), displaced families receive the longer-term direct rental assistance and wrap-around case management services needed to find permanent housing solutions, secure employment, and connect to public benefits. DHAP was created after hard-won lessons from Hurricane Katrina, and it has been used

successfully in major storms since. DHAP has been upheld as a best practice by past Republican and Democratic administrations. DHAP was designed to help low-income survivors who face significant barriers to accessing FEMA's Transitional Shelter Assistance (TSA) motel program and who need longer-term housing stability to fully recover. TSA is not well-suited for low income survivors because hotels often charge daily "resort" fees on top of FEMA reimbursements, require security deposits, or require that displaced households have credit cards—all of which are barriers to low income households who have already depleted any savings that they may have had and who are often unbanked or underbanked. TSA also relies on arbitrary, short-term deadlines—often giving survivors only a few days or hours' notice—and creates burdensome hoops that families must jump through to use the program. Without DHAP, displaced, low-income families often have little choice but to double or triple up with other low-income families, return to uninhabitable homes, or pay more than half of their limited incomes on rent, making it harder to meet their other basic needs. Survivors without stable, affordable homes face a higher risk of evictions and, in worst cases, homelessness. There are numerous accounts of individuals unable to access TSA after the 2017 disasters who set up "tent cities" or who later needed emergency hospital care after returning to mold-infested homes. Families were pushed into homelessness because they had no place to go. Despite the clear need, FEMA has refused to activate DHAP, rejecting requests by Governors, dozens of members of Congress, survivors, and advocates. For more information, see NLIHC's DHAP factsheet and a comparison of DHAP and alternative programs.

TOP PRIORITIES FOR ANY DISASTER RECOVERY PACKAGE

Priority #2: Direct FEMA to activate DHAP, using legislative language from S. 2996, the "Housing Victims of Major Disasters Act of 2018," introduced by Senator Elizabeth Warren (D-MA), and S.2880, the "Disaster Housing Assistance Act," introduced by Senator Bill Nelson. Alternatively, Congress should directly appropriate DHAP funds.

REQUIRE ALL DAMAGED OR DESTROYED FEDERALLY SUBSIDIZED AFFORDABLE RENTAL HOMES TO BE REPLACED ON A ONE-FOR-ONE BASIS.

America's rental housing crisis directly impacts all states and congressional districts. Even before a disaster hits, most of the lowest-income families living in these communities pay more than half of their limited incomes on rent, leaving few resources to help meet their other basic needs, including food, childcare, healthcare, and transportation. After past disasters, affordable housing stock is often lost and never rebuilt, exacerbating the affordable rental housing crisis in these communities and displacing low-income families. Developments should be rebuilt in both high-opportunity communities outside of the floodplain with access to good schools, jobs, healthcare, and transit, and in distressed communities as part of a comprehensive revitalization plan.

Priority #3: Require states receiving CDBGDR funding ensure that all damaged or destroyed federally subsidized affordable rental homes are replaced on a one-for-one basis. Congress should use legislative language from H.R. 4557, the "Reforming Disaster Recovery Act," introduced by Representative Ann Wagner (R-MO).

Priority #4: Provide the deeply targeted resources that states need to replace all damaged or destroyed federally subsidized affordable rental homes, including:

- National Housing Trust Fund, a new federal resource designed specifically address the shortage of affordable housing for people with the greatest needs;
- HOME Investment Partnerships Program;
- Low-Income Housing Tax Credits, along with broadly supported modifications to increase efficiency and flexibility and to expand the program's reach—including to the lowest income households—as included in the Affordable Housing Credit Improvement Act;
- New Markets Tax Credits; and
- Technical Assistance and Capacity Building.

ENSURE THAT FEDERAL DISASTER RECOVERY DOLLARS ARE USED EQUITABLY TO ADDRESS HOUSING AND INFRASTRUCTURE NEEDS.

Congress relies on FEMA and HUD's unmet needs assessment to determine the amount of disaster recovery funding needed to rebuild damaged and destroyed homes and infrastructure. After past disasters, however, states have used federal disaster recovery resources slated for housing recovery for other purposes. Congress has an important role to play to ensure that federal dollars are spent effectively and for the specific purpose for which they were allocated.

Priority #5: Require states receiving federal disaster recovery funding to allocate CDBGDR resources equitably to address their housing and infrastructure needs, according to FEMA and HUD's assessments and other data. Congress should use legislative language from H.R. 4557, the "Reforming Disaster Recovery Act," introduced by Representative Ann Wagner (R-MO). According to news reports, FEMA has denied Individual Assistance to an estimated 60 percent of Hurricane Maria survivors—twice the rate for Hurricane Harvey survivors—due largely to title issues prevalent in Puerto Rico that make it difficult for families to prove ownership of their homes. To overcome this challenge, DHRC members worked with FEMA to create an alternative form that disaster survivors could use to prove ownership. While FEMA has accepted this form, there are widespread problems that raise serious due process concerns—the forms are not available at Disaster Recovery Centers (DRCs) or on FEMA's website or social media,

and the form was not attached to the agency's press release announcing that the form was available. Unaware of the new form, staff at DRCs have turned away survivors. Instead of making the form available, FEMA is referring survivors to 3rd party legal aid organizations.

Priority #6: Direct FEMA to notify all Hurricane Maria survivors—including those who were denied assistance because of title issues—and to share with them a copy of the new form and information about how they can appeal their cases.

ENSURE THAT FEDERAL DISASTER RECOVERY DOLLARS ARE USED EQUITABLY TO ADDRESS THE NEEDS OF HOMEOWNERS, RENTERS, AND PEOPLE EXPERIENCING HOMELESSNESS.

Under current law, states are not required to allocate federal disaster recovery funding to equitably address the needs of homeowners, renters, and people experiencing homelessness prior to the disaster, as identified in FEMA and HUD's assessments and other data. As a result, after past disasters, states have diverted resources away from people with the greatest needs—including low-income renters and people experiencing homelessness—to relatively higher-income homeowners. In a 2010 report, the GAO recommended that Congress provide more direction to states in how to allocate funds from the CDBGDR program. The report concludes, "Without specific direction on how to better target disaster-related CDBGDR funds for the redevelopment of homeowner and rental units after future disasters, states' allocations of assistance to homeowners and renters may again result in significant differences in the level of assistance provided."

Priority #7: Direct HUD to implement the GAO's recommendation to provide states with specific direction on how to allocate disaster recovery dollars equitably between homeowners, renters, and people experiencing homelessness prior to the disaster, according to FEMA and HUD's unmet needs assessment and other data. Congress should use legislative language from H.R. 4557, the "Reforming Disaster Recovery Act," introduced by Representative Ann Wagner (R-MO). FEMA has interpreted current law to deny assistance to people experiencing homelessness prior to the disaster, despite their exceptional needs. These individuals should have access to the same emergency shelter and disaster relief assistance as those who were renting their homes prior to the disaster.

Priority #8: Enact clarifying legislation to ensure that people experiencing homelessness prior to the disaster have access to the same emergency shelter and disaster relief assistance as renters, including rental assistance. Congress should also provide targeted resources—such as Continuum of Care grants—to help serve people who were experiencing homelessness prior to the disaster, whose needs are frequently overlooked.

SUPPORT INNOVATIVE, COST-EFFECTIVE HOUSING SOLUTIONS.

RAPIDO was developed after Hurricane Dolly to provide displaced households with cost-effective, temporary-to-permanent housing solutions. Under RAPIDO, families have access to a core, modular home—assembled on-site—where they can live during the lengthy recovery process. During this time, the core home can be expanded to meet the long-term needs of the family. RAPIDO provides both immediate shelter and the foundation for a permanent home. It is an innovative solution that costs less than current federal practices of providing temporary shelter and then rebuilding a separate, permanent structure later.

Priority #9: Include legislative language to allow states to use federal recovery resources to create a RAPIDO demonstration program.

PROMOTE CONTRACTING AND JOBS FOR LOW-INCOME DISASTER SURVIVORS AND BUSINESSES.

To help stimulate local economies and ensure that low-income communities are built back stronger, Congress should ensure job training and employment opportunities for low-income residents, as well as contract opportunities for small businesses in connection with projects and activities in their neighborhoods. Section 3 is also a tool to overcome likely labor shortages after a disaster.

Priority #10: Direct HUD to use Section 3 to promote job training and employment opportunities for low-income residents in the recovery process. Congress should revise and improve Section 3 to make the program more impactful.

PREPARE FOR THE NEXT DISASTER.

Rebuilding homes and infrastructure to be better prepared to withstand future disasters is plain common sense. While we cannot prevent disasters, we can decrease the risk that these disasters pose. Through planning and mitigation, communities are better able to maintain vital functions during an emergency and recover more efficiently. Congress provided mitigation funds to help communities recover from the 2017 disasters.

Priority #11: Provide funds specifically targeted to address mitigation strategies and ensure that all rebuilding efforts meet mandatory mitigation standards.

AUTHORIZE LONG-TERM DISASTER RECOVERY LEGISLATION.

DHRC supports H.R. 4557, the "Reforming Disaster Recovery Act" introduced by Rep. Ann Wagner (R-MO). The bill permanently authorizes the Federal Government's primary long-term disaster rebuilding program, the CDBGDR program, which provides states and communities with the flexible resources needed to rebuild affordable housing and infrastructure after a disaster. The bill also establishes important safeguards and tools to help ensure that federal disaster recovery and rebuilding efforts reach all impacted households, including those with the lowest incomes who are often the hardest-hit by disasters and have the fewest resources to recover.

Priority #12: Enact H.R. 4557, the "Reforming Disaster Recovery Act," introduced by Representative Ann Wagner (R-MO) to permanently authorize and reform CDBGDR.

Appendix 8

The Storm after the Storm: Disaster, Displacement and Disability Following Hurricane Florence

February 5, 2019: The Storm after the Storm, issued by Disability Rights North Carolina, provides strong evidence that federal, state and local emergency management officials must act to ensure the well-being of people with disabilities during natural disasters. Analyzing the response to Hurricane Florence, the report shows how public officials must do more to include people with disabilities and their advocates in planning for future emergencies to ensure their safety.

Endnotes

1 Lakin, K. C., S. Larson, P. Salmi, and A. Webster. (2010). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2009. Research and Training Center on Community Living. Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota. Accessed July 21, 2011. http://rtc.umn.edu/docs/risp2009.pdf (April 18, 2019).

2 National Council on Disability, "The Needs of People with Disabilities with Psychiatric Disabilities During and After Hurricanes Katrina and Rita: Position Paper and Recommendations" 2014 The Needs of People with Disabilities with Psychiatric Disabilities During and After Hurricanes Katrina and Rita.

3 2017 Hurricane Season FEMA After-Action Report July 12 ,2018, p.1.

4 U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. "Disability impacts all of us." https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html.

5 Marcie Roth, Kailes June, and Melissa Marshall. Partnership for Inclusive Disaster Strategies. "Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters." May, 2018. http://www.disasterstrategies.org/index.php/news/partnership-releases-2017-2018-after-action-report.

6 US Department of Health and Human Services, Centers For Disease Control and Prevention. "CDC: 1 in 4 US adults live with a disability." (April 18, 2019).

7 Department of Homeland Security Civil Rights Evaluation Tool OMB Control No. 1601-0024.

8 Marcie Roth, Kailes June, and Melissa Marshall. Partnership for Inclusive Disaster Strategies. "Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters." May, 2018. http://www.disasterstrategies.org/index.php/news/partnership-releases-2017-2018-after-action-report.

9 CNN News. 2017. "Harvey aftermath: Houston 'open for business'; other cities suffering." August 31, 2017 https://www.cnn.com/2017/08/31/us/harvey-houston-texas-flood/index.html.

10 PBJ Daily Nurse Staffing CY 2017 Q2: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Daily-Nurse-Staffing-CY-2017-Q2/utrm-5phx.

11 PBJ Daily Nurse Staffing CY 2017 Q3: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Daily-Nurse-Staffing-CY-2017-Q3/bpnu-uej3.

12 PBJ Daily Nurse Staffing CY 2017 Q4: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Daily-Nurse-Staffing-CY-2017-Q4/4z4g-bf8w.

13 PBJ Daily Nurse Staffing CY 2017 Q2: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Daily-Nurse-Staffing-CY-2017-Q2/utrm-5phx.

14 PBJ Daily Nurse Staffing CY 2017 Q3: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Daily-Nurse-Staffing-CY-2017-Q3/bpnu-uej3.

15 PBJ Daily Nurse Staffing CY 2017 Q4: https://data.cms.gov/Special-Programs-Initiatives-Long-Term-Care-Facili/PBJ-Daily-Nurse-Staffing-CY-2017-Q4/4z4g-bf8w.

16 Ibid.

17 Eschenbacher, H.J. (2018). Change in ICF/IID residents in Louisiana 2002 to 2009 by facility size [customized analysis]. Minneapolis: University of Minnesota, Residential Information Systems Project. See the chart gallery at RISP.UMN.EDU for more information.

18 Ibid.

19 Ibid.

20 Ibid.

21 Ibid.

22 Ibid.

23 Marcie Roth, Kailes June, and Melissa Marshall. Partnership for Inclusive Disaster Strategies. "Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters." May, 2018. http://www.disasterstrategies.org/index.php/news/partnership-releases-2017-2018-after-action-report.
24 U.S. Department of Homeland Security. "Civil Rights Evaluation Tool." https://www.dhs.gov/sites/default/files/publications/dhs-civil-rights-evaluation-tool.pdf.
25 U.S. Senate. "Sheltering in Danger: How Poor Emergency Planning and Response Put Nursing Home Residents at Risk During Hurricanes Harvey and Irma." November, 2018. https://www.finance.senate.gov/imo/media/doc/Sheltering%20in%20Danger%20Report%20(2%20Nov%202018).pdf.
26 Ewa Borowiak, and Tomasz Kostka. 2004. Predictors of Quality of Life in Older People Living at Home and Institutions. Aging clinical and experimental research. 16. 212-20. 10.1007/BF03327386.
27 S.H. Al-Mashoor, S.A. Hashim, and A.W. Nikmat. 2015. "Quality of Life in People with Cognitive Impairment: Nursing Home Versus Home Care." International Psychogeriatrics. 2015 (27: 815-824).
28 B. Baca, D. Chandran, R. Chapin, S. Leedal, K.R. Macmillan, P. Oslund, R. Rachlin, and M. Zimmerman. 2007. "The Community Tenure Study: Community Status of CARE Assessment Customers 60 Months After Diversion." https://crado.ku.edu/projects/dc-tenure/nursingfacility-hcbs.
29 J.Robinson, et al. 2015. "Connecticut Money Follows the Person Yields Positive Results for Transitioning People with Disabilities out of Institutions." Health Affairs, vol 34 No 10. https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2015.0244.
30 U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services."Money Follows the Person." https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html.
31 Erika Pesantes. 2017. "14th Person From Hollywood Nursing Home Dies, Police Say." Sun Sentinel. October 9, 2017. https://www.sun-sentinel.com/news/hollywood-nursing-home-hurricane-deaths/fl-reg-13-nursing-home-death-20171009-story.html.
32 Jaycey Fortin. 2107. "Behind the Photo of the Older Women in Waist High Water in Texas." New York Times. August 28,2017. https://www.nytimes.com/2017/08/28/us/nursing-home-houston-texas.html.
33 U.S. Senate. 2018. "Sheltering in Danger: How Poor Emergency Planning and Response Put Nursing Home Residents at Risk During Hurricanes Harvey and Irma." p. 78.
34 Ibid. p.70.
35 Ibid. p.5.
36 Ibid. p.2.
37 Tyler Pager, Campbell Robertson, and Chris Dixon. 2018. "They Were Seeking Mental Health Care. Instead They Drowned in a Sheriff's Van" New York Times. Sept. 19, 2018. *https://www.nytimes.com/2018/09/19/us/women-drown-van-south-carolina-floods.html.*
38 Tyler Pager, Campbell Robertson, and Chris Dixon. 2018. "They Were Seeking Mental Health Care. Instead They Drowned in a Sheriff's Van" New York Times. Sept. 19, 2018. *https://www.nytimes.com/2018/09/19/us/women-drown-van-south-carolina-floods.html.*
39 Ibid.
40 U.S. Department of Justice, " ADA Best Practices Tool Kit for State and Local Governments," https://www.ada.gov/pcatoolkit/chap7shelterprog.htm#6.
41 Ibid.
42 U.S. Department of Justice, " ADA Best Practices Tool Kit for State and Local Governments," https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm.
43 U.S. Department of Justice, "ADA Tool Kit," Chapter 7 Addendum 2, https://www.ada.gov/pcatoolkit/chap7shelterprog.htm.
44 U.S. Department of Homeland Security Office for Civil Rights and Civil Liberties, FEMA Office of Equal Rights, and FEMA Office of Disability Integration & Coordination. "Notice from the U.S. Department of Homeland Security Office for Civil Rights and Civil Liberties, FEMA Office of Equal Rights, and FEMA Office of Disability Integration & Coordination." https://www.dhs.gov/sites/default/files/publications/notice-nondiscrimination-during-disasters.pdf.

45 U.S. Department of Justice, " ADA Best Practices Tool Kit for State and Local Governments," https://www.ada.gov/pcatoolkit/chap7shelterprog.htm#6.
46 U.S. Department of Homeland Security, Federal Emergency Management Agency (FEMA). 2010. "Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters." November 2010. https://www.fema.gov/media-library-data/20130726-1831-25045-7316/fnss_guidance.pdf.
47 U.S. Department of Homeland Security, Federal Emergency Management Agency (FEMA). 2010. "Accommodating Individuals with Disabilities in the Provision of Disaster Mass Care, Housing, and Human Services." May 2010. https://www.fema.gov/media-library-data/20130726-1617-20490-6430/section689referenceguide.pdf.
48 Department of Health and Human Services. 2018. "OCR Issues Guidance to Help Ensure Equal Access to Emergency Services and the Appropriate Sharing of Medical Information During Hurricane Florence." September 13, 2018.
49 U.S. Department of Health and Human Services, "Working with Older Adults and People with Disabilities: Tips for Treatment and Discharge Planning." Last reviewed December 2017. https://www.phe.gov/Preparedness/planning/abc/Pages/elderly-disabled.aspx.
50 U.S. Department of Health and Human Services, "Public Health Emergency Public Health and Medical Emergency Support for a Nation Prepared." https://www.phe.gov/about/sns/Pages/products.aspx.
51 US Department of Health and Human Services, Centers for Medicare and Medicaid Services. "Additional Emergency and Disaster-Related Policies and Procedures That May Be Implemented Only With a § 1135 Waiver." September 14, 2018. https://www.cms.gov/About-CMS/Agency-Information/Emergency/Downloads/MedicareFFS-EmergencyQsAs1135Waiver.pdf.
52 U.S. Department of Health and Human Services. 2018. "OCR Issues Guidance to Help Ensure Equal Access to Emergency Services and the Appropriate Sharing of Medical Information During Hurricane Florence."
53 U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services, "Durable Medical Equipment, Prosthetics, Orthotics, and Supplies for Medicare Beneficiaries Impacted by an Emergency or Disaster."
54 U.S. Department of Justice, "ADA Tool Kit," Chapter 7 Addendum 2. https://www.ada.gov/pcatoolkit/chap7shelterprog.htm.
55 U.S. Department of Health and Human Services. "Emergency Support Function #8 – Public Health and Medical Services Annex". June 2016. https://www.fema.gov/media-library-data/1470149644671-642ccad05d19449d2d13b1b0952328ed/ESF_8_Public_Health_Medical_20160705_508.pdf.
56 US Department of Homeland Security National Response Framework 3rd Edition June 2016. https://www.fema.gov/media-library-data/1466014682982-9bcf8245ba4c60c120aa915abe74e15d/National_Response_Framework3rd.pdf page 38.
57 Roth, Kailes, Marshall, "Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters." Appendix G.
58 National Mass Care Council. 2017. "Multi-Agency Sheltering/Sheltering Support Plan Template: Tab A to Appendix F Transition to Alternate Sheltering and Housing Solutions Considerations." updated March 2017. http://nationalmasscarestrategy.org/wp-content/uploads/2018/03/Appendix-F-Transition-to-Alternate-Sheltering-Final-Version.pdf.
59 U.S. Department of Housing and Urban Development, "Section 504: Frequently Asked Questions." https://www.hud.gov/program_offices/fair_housing_equal_opp/disabilities/sect504faq.
60 Ibid.
61 Rose Hoban. 2018. "Inside and Emergency Medical Hurricane Shelter" North Carolina health News." September 21, 2018. https://www.northcarolinahealthnews.org/2018/09/21/inside-an-emergency-hurricane-medical-shelter/.
62 U.S Department of Justice, ADA Tool Kit. Chapter 7, Addendum 2. https://www.ada.gov/pcatoolkit/chap7shelterprog.htm.
63 North Carolina Emergency Management. "Special Medical Needs Shelters: A Preparedness Guide." https://www.scdhec.gov/sites/default/files/Library/ML-025588.pdf.

64 U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. "Centers for Medicare and Medicaid Services Emergency Preparedness Rule." https://www.cms.gov/medicare/provider-enrollment-and-certification/surveycertemergprep/emergency-prep-rule.html.
65 U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. "Centers for Medicare and Medicaid Services Emergency Preparedness Rule." https://www.cms.gov/medicare/provider-enrollment-and-certification/surveycertemergprep/emergency-prep-rule.html.
66 Burch and Joyner. *Unspeakable: The Story of Junius Wilson* (Caravan Book, 2007).
67 U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response, Public Health Emergency, Public Health and Emergency Support for a Nation Prepared. https://www.phe.gov/Preparedness/support/medical assistance/Pages/default.aspx.
68 Caley, Sylvia B. "The Olmstead Decision: The Road to Dignity and Freedom." Georgia State University Law Review Volume 26 Issue 3 Spring 2010 https://readingroom.law.gsu.edu/cgi/viewcontent.cgi?article=2407&context=gsulr.
69 U.S. Department of Homeland Security, Federal Emergency Management Agency (FEMA), "FEMA P-361 Safe Rooms for Tornadoes and Hurricanes: Guidance for Community and Residential Safe Rooms" https://www.fema.gov/media-library/assets/documents/3140.
70 Department of Homeland Security. "Civil Rights Evaluation Tool, OMB Control No. 1601-0024." https://www.dhs.gov/sites/default/files/publications/dhs-civil-rights-evaluation-tool.pdf.
71 U.S. Department of Justice, " ADA Best Practices Tool Kit for State and Local Governments," https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm.
72 Josh Shaffer, Martha Quillin. 2018. "Evacuated and evicted, many of Hurricane Florence's victims have nowhere to go." The News & Observer. October 07, 2018. Updated November 14, 2018.
73 National Low Income Housing Coalition. "Disaster Recovery Housing." https://nlihc.org/explore-issues/projects-campaigns/disaster-housing-recovery.
74 Lynn Hatter Mar 20, 2019, WJCT Public Media " Bay Schools Superintendent Talks Homelessness, Mental Health Struggles Of Students" https://news.wjct.org/post/bay-schools-superintendent-talks-homelessness-mental-health-struggles-students.

Lakin, K. C., S. Larson, P. Salmi, and A. Webster. (2010). Residential Services for Persons with Developmental Disabilities: Status and Trends through 2009. Research and Training Center on Community Living. Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota. Accessed July 21, 2011. http://rtc.umn.edu/docs/risp2009.pdf (accessed April 18, 2019).