



# ENSURE EMERGENCY DISASTER RESPONSE MEETS NEEDS OF PEOPLE WITH SMA

*Support the Real Emergency Access for Aging and Disability Inclusion for Disasters Act and Disaster Relief Medicaid Act*

## DID YOU KNOW?

- U.S. weather-related events that resulted in more than \$1 billion in damages are on the rise, averaging 10 or more annually for six consecutive years and totaling nearly 300 since 1989. ([Source: National Oceanic and Atmospheric Administration](#))
- State and local officials of areas impacted by recent hurricanes identified barriers for people with disabilities in accessing food and water, medication and medical care, emergency shelter, and transportation during an emergency. ([Source: U.S. Government Accountability Office](#))
- Eligibility for Medicaid home and community-based services (HCBS) differs by state and services are not transferable. If a person with a disability who relies on a personal care attendant or other HCBS support relocates to another state—whether displaced by a natural disaster or by choice—the individual must meet eligibility requirements for the new state, which may have HCBS waiting lists. ([Source: Centers for Medicare & Medicaid Services](#))
- Inclusive emergency preparedness was among the top priorities identified by individuals with spinal muscular atrophy (SMA). ([Source: Cure SMA](#))

## WHY CONGRESS SHOULD ACT

Despite agency initiatives, such as FEMA's [Office of Disability Integration and Coordination](#), and public awareness campaigns, such as [Ready.gov](#), state and local governments and their partners reported challenges in providing disaster-related assistance to people with disabilities and older adults, according to a [recent U.S. Government Accountability Office \(GAO\)](#) study. One adult with SMA, for example, reported having to ask for help on social media to safely evacuate from her flooded home during a recent hurricane. In addition, people with disabilities who rely on HCBS, such as personal care attendants, may also risk losing their lifeline to independence if they are displaced by a natural disaster and forced to relocate to a different state. The GAO recommended inclusive preparedness planning, additional training, and simplified disaster relief registration, among other things for government agencies to improve their disaster response for people with disabilities.

## CURE SMA POSITION

To help states and localities effectively respond to the needs of people with SMA and other disabilities during times of disaster, Cure SMA supports the following emergency preparedness legislation.

- The **Real Emergency Access for Aging and Disability Inclusion for Disasters (REAADI) Act** helps states and localities plan for and respond to the health, safety, and independence of people with disabilities before, during, and after disasters. The legislation, among other things, would fund research, provide training and technical assistance, ensure uninterrupted access to Medicaid services when a recipient crosses state lines, and include oversight and accountability measures for inclusive emergency preparedness and response.
- The **Disaster Relief Medicaid Act** would ensure that individuals eligible for Medicaid who are forced to relocate due to a disaster can retain access to their Medicaid-supported services. The legislation would provide states with resources to support the Medicaid needs of individuals forced to relocate following a disaster and develop an emergency response corps to provide HCBS in emergency situations.



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Cure SMA is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.