

Disaster Planning for People with Disabilities

Request: Co-Sponsor the Real Emergency Access for Aging and Disability Inclusion in Disasters Act (READI) and Disaster Relief Medicaid Act (DRMA)

Background on Disaster Planning

- People with disabilities are two to four times more likely to be critically or fatally injured in a disaster.¹
- The adoption of “inclusive disaster strategies” would assure the inclusion of people with disabilities and older adults in the planning, response, recovery and mitigation of disasters, and is a recommended strategy for minimizing the most harmful effects of disasters on vulnerable populations.
- People eligible for Medicaid that are forced to leave their state due to a disaster should be assured of continued access to ongoing coverage, treatment and care in their adopted state.

Vital Components of Disaster Planning

The Real Emergency Access for Aging and Disability Inclusion in Disasters Act (READI) (S. 1755/Casey and Collins, H.R. 3208/Langevin)

- Ensures a strong voice for older adults and people with disabilities in the preparation, response, recovery and mitigation of disasters by:
 - Involving people with disabilities in emergency preparedness and response plans before, during and after a disaster;
 - Establishing a National Commission on Disability Rights and Disasters to recommend best practices in coordinated disaster response efforts at the local, state and federal levels;
 - Providing training and technical assistance centers to aid states before, during and after disasters; and
 - Ensuring that disaster relief funding and expenditures comply with the Rehabilitation Act, Americans with Disabilities Act and other civil rights protections.

The Disaster Relief Medicaid Act (DRMA)

(S. 1754/Casey, H.R. 3215/Shalala and Gonzalez-Colon)

- Ensures continuity of care and access to Medicaid services when recipients must evacuate across state lines; and
- Guarantees that a 100 percent federal matching payment for medical assistance is provided to state Medicaid programs in recipients’ adopted states.

What is multiple sclerosis (MS)?

- MS is an unpredictable, often disabling disease of the central nervous system.
- Symptoms range from numbness and tingling to blindness and paralysis.
- The progress, severity and specific symptoms of MS in any one person cannot yet be predicted.
- Nearly 1 million people are living with MS in the United States—more than twice the previously reported number.

Disaster Planning for People with Disabilities

My life as a clinical neuropsychologist ended when I was diagnosed with primary progressive MS at the age of 37.

It was devastating. I had worked so long and hard to create a life I thought was meaningful, and it was taken away. I was left to pick up the pieces and start over with “Plan B.”

My “Plan B” included moving from Miami, FL to Jackson, MS to be closer to family.

I often mention that people with disabilities are “tough,” but we’re also vulnerable in ways others aren’t. We frequently have to overcome obstacles that others don’t even notice, but we also have few or no “backup systems” should something go wrong. What may be an inconvenience for others can be dangerous to us.

Here’s what I mean: When there’s a disaster, I cannot self-evacuate like other people. I use a power wheelchair for mobility and can no longer drive. That’s precisely why I chose to leave Miami in 2006 and return to Jackson.

The irony, though, is that I’m still in the cross-hairs of flooding!

During heavy rains that occur roughly twice a year, my entire street floods under several feet of water, threatening everyone on it.



Scott Crawford, PhD at his home in Jackson, Mississippi.

“Living with Progressive MS is hard enough without the added stress of playing ‘disaster roulette.’ ”

I have a disaster readiness kit, but due to my disability, it is impossible for me to transport without help. When flood waters rise, my street and home are suddenly cut off, surrounded by rushing water. I cannot just step into a boat. My power wheelchair weighs 421 lbs. (600 lbs. with me), and I depend upon it for mobility. It IS my legs. Leaving it behind would be a disaster in itself because it lists for \$60,000. Whenever we get a heavy rain I wonder, “Is this the day I’ll lose everything?”

If people like me were included in the process of planning for disasters, my need for a safe way to evacuate from my home, and with my power wheelchair, would probably have been worked out by now.

ⁱ Paul Timmons, “Disaster Preparedness and Response: The Special Needs of Older Americans,” Statement for the Record, Special Committee on Aging, U.S. Senate, September 20, 2017, available

at https://www.aging.senate.gov/imo/media/doc/SCA_Timmons_09_20_17.pdf.