



THE PARTNERSHIP

FOR INCLUSIVE DISASTER STRATEGIES

To: Senate Health, Education, Labor, and Pensions (HELP) Committee

From: The Partnership for Inclusive Disaster Strategies

Re: Comments on Discussion Draft on the Pandemic and All-Hazards Preparedness Act (PAHPA) Reauthorization 2023

Date: July 10, 2023

Senate HELP Committee
428 Senate Dirksen Office Building
Washington, DC, 20510

Dear Chairman Sanders and Ranking Member Cassidy,

The Partnership for Inclusive Disaster Strategies (The Partnership) is the only U.S. disability-led organization with a focused mission of equity for people with disabilities and people with access and functional needs throughout all planning, programs, services and procedures before, during and after disasters and emergencies.

We achieve our mission through disability-led disaster response and community resilience; community engagement, organizing and leadership development; advocacy and systems change, training, technical assistance and research; and unwavering support for local disability organizations.

The Partnership is providing comments on the Discussion Draft of the Pandemic and All Hazards Preparedness Act Reauthorization of 2023 [To reauthorize certain programs under the Public Health Service Act and the Federal Food, Drug, and Cosmetic Act with respect to public health security and all-hazards preparedness and response, and for other purposes.]

The Partnership has advocated that the Real Emergency Access for Aging and Disability Inclusion for Disasters Act (READI) S.1049 / H.R.2371, be incorporated as a title of the Pandemics and All Hazards Preparedness Act Reauthorization of 2023. The Partnership



THE PARTNERSHIP

FOR INCLUSIVE DISASTER STRATEGIES

maintains that all provisions of READI are necessary to provide equal access to disaster-related programs and services to people with disabilities, including older adults with disabilities (the vast majority of older adults), older adults without disabilities, and other people with access and functional needs. As a result of providing equal access to disaster-related programs and services, institutionalization of people with disabilities including older adults, during disasters and public health emergencies will be reduced. This will mitigate illness and earlier death of people with disabilities, including older adults. It will also result in other better health outcomes overall.

Section 304 of PAHPA attempts to incorporate a few aspects of READI into PAHPA. However, it does this without capturing the essential core components of READI. These include protecting the legal rights of people with disabilities, including older adults with disabilities, during disasters, and ensuring that people with disabilities, including older adults, have significant input in the process of advising, implementing, and maintaining technical assistance centers and other aspects of the proposed initiative.

The Partnership asks that the sense of Congress articulated in READI be reflected in PAHPA. This sense of Congress recognizes that people with disabilities and older adults “must be included as key speakers, essential stakeholders, and decision makers in the preparation (this includes planning), response, recovery, and mitigation phases of disasters;” and, that “individuals with disabilities and older adults must be included in the evaluation of governmental, VOAD [Voluntary Organizations Active in Disasters], and other governmental preparation (including planning), response, recovery, and mitigation of disasters.”

It also requests that the proposed legislation reflect the purpose of READI. This includes to “ensure compliance with the Americans with Disabilities Act of 1990, the Rehabilitation Act of 1973, and other disability rights laws. It also includes to improve coordination among communities of individuals with disabilities and older, including multiply marginalized Black Indigenous People of Color and LGBTQ+ communities, government agencies, centers for independent living, VOADS, and other non-governmental organizations...”



THE PARTNERSHIP

FOR INCLUSIVE DISASTER STRATEGIES

The Partnership supports section 304 in part. Establishment of more than one technical assistance center is vitally necessary and can prevent costly, overly restrictive, and hazardous institutionalization. It can also promote better overall health outcomes and community resilience.

Although section 304 is titled “Supporting Individuals with Disabilities During Emergency Responses,” it is not clear how provisions of section 304 (a) “Technical Assistance Centers on At-risk Individuals and Disasters” will be utilized to benefit people with disabilities. However, as drafted it is not clear that people with disabilities, including older adults with disabilities, will be adequately included in the establishment, management, and oversight of the technical assistance center(s). It is unclear who will receive services, what services will be provided by technical assistance centers, and whether or not protecting the rights of people with disabilities, including older adults with disabilities, will be a priority of the technical assistance centers. REAADI acknowledged the civil rights protections of people with disabilities, including older adults with disabilities, and that lack of compliance with these laws poses a significant threat to the health and safety of people with disabilities, including older adults with disabilities in disasters and emergencies.

The term “at-risk” is used to describe the people who will be the focus of the technical assistance centers in the proposed legislation. It is defined as “(A) Taking into account the public health and medical needs of at-risk individuals, including the unique needs and considerations of individuals with disabilities, in the event of a public health emergency. (B) For the purpose of this chapter, the term “at-risk individuals” means children, pregnant women, senior citizens and other individuals who have access or functional needs in the event of a public health emergency, as determined by the Secretary.” Use of this term makes the intent of the proposed legislation somewhat ambiguous. It potentially suggests a shift in focus from equal access to services during disasters and emergencies and protection of civil rights to medical needs.

The needs of people with disabilities are not “unique” as stated in this definition. People with disabilities, like people without disabilities, need the same disaster-related programs and services. What is different is that people with disabilities are often denied access to these services. Examples of this include denying a person with a disability access to a shelter



THE PARTNERSHIP

FOR INCLUSIVE DISASTER STRATEGIES

because they have a service animal or excluding people with communication disabilities from participation by not providing auxiliary aids and services, such as sign language interpreters when they are legally required. Beyond this, given that it is acknowledged that at least 27 percent of all people in the US have disabilities, it is not viable to describe the needs of people with disabilities as “unique.”

In addition, The Partnership opposes the sunset provision for section 304 (a) in the proposed legislation. Given that people with disabilities are two to four times more likely to die or be injured in disasters than nondisabled people, the increased prevalence and severity of disasters and the pervasiveness of denial of equal access to people with disabilities, it is unrealistic to expect that people with disabilities, including older adults with disabilities, will realize full inclusion and not need support in disasters roughly four years after enactment.

The Partnership is in support of section 304 (b) Crisis Standards of Care in the issuing of guidance to state and localities to develop or modify their crisis standards of care during public health emergencies or presidentially declared disasters or emergencies to ensure they do not discriminate on the basis of disability or age. We strongly encourage the Committee to consider including section 1557 of the Patient Protection and Affordable Care act (42 U.S.C. 18116) to the nondiscrimination requirements to include race, color, national origin, or sex, as it is recommended in READI.

The Partnership is opposed to the proposed composition of the National Advisory Committee on Individuals with Disabilities and Disasters as drafted in section 305. When enacting legislation, Congress has often adhered to the disability rights movement value of “nothing about us without us.” This means among other things, that people with disabilities must have a simple majority (51 percent) on advisory and governing boards and councils of disability organizations. This includes the National Council on Disability as well as Centers for Independent Living. This Advisory Committee and organizations funded to provide technical assistance or other services of the program should also be led by people with disabilities.



THE PARTNERSHIP

FOR INCLUSIVE DISASTER STRATEGIES

Since disabled people of color as well as disabled people from other marginalized groups are even more disproportionately impacted by disasters, it is critical that they are represented on the Advisory Committee and in contracted organizations. In addition to being disability-led, the Advisory Committee and entities that the initiative contracts with should also be diverse in race, ethnicity, gender, gender identity and sexual orientation, and veteran status as is the case in REAADI.

Thank you for this opportunity to comment.