



REAAI (REAL EMERGENCY ACCESS FOR AGING AND DISABILITY INCLUSION) IN DISASTERS ACT

The Issue

In recent years, this nation has experienced several catastrophic natural disasters, from Category 4 and 5 hurricanes to devastating wildfires, floods, and earthquakes. Preparing for, responding to, and recovering from disasters requires a coordinated effort among federal, state, territorial, tribal, local, and non-governmental entities. It also requires recognition that, while individuals bear some responsibility to prepare for emergency situations, public entities, and recipients of federal funds must take into account the rights of people with disabilities in the implementation of their emergency management plans.

Too often, however, America's 61 million individuals with disabilities and 48 million older adults are overlooked in preparation for, management of, and recovery from natural and man-made disasters. During disasters, people with disabilities and older adults are two to four times more likely to be injured or die due to inadequate planning and lack of equal access to disaster programs and services. Many more are inappropriately institutionalized.

PVA's Position

PVA supports the REAAI in Disasters Act, which will soon be introduced by Sen. Robert Casey (D-PA). This legislation aims to respond to recent failures on the part of the nation's emergency management system to fully integrate people with disabilities into plans for responding to natural and man-made disasters. REAAI creates a network of centers focused on research, training, and technical assistance to help states and localities to better involve and support people with disabilities and older adults during times of disasters. It establishes a National Commission on Disability Rights and Disasters to study the needs of individuals with disabilities, older adults, and others with access and functional needs. It requires a review of the spending of disaster funds to ensure people with disabilities and older adults have access to services and that buildings and structures reconstructed following disasters are accessible. The bill also requires the Department of Justice to examine how civil rights of people with disabilities and older adults are treated during and following disasters.

The REAAI in Disasters Act has been endorsed by almost 100 state and national organizations. PVA urges members of the Senate to cosponsor this important legislation and work for its passage during this Congress. Any member interested in becoming a cosponsor should contact Josh Dubensky in Senator Casey's office at Josh_Dubensky@aging.senate.gov. Efforts are also underway to find a House sponsor for REAAI. Interested House members are encouraged to contact Senator Casey's office to discuss opportunities to engage with this legislation.



IMPROVEMENTS TO THE SPECIALLY ADAPTED HOUSING PROGRAM

The Issue

Veterans and service members who have sustained certain severe service-connected disabilities are eligible for grants to assist with the building, remodeling, or purchasing of an adapted home.

The Specially Adapted Housing (SAH) grant allows modifications to be made to a residence to give a veteran or service member greater independence. One example of a modification is making a home wheelchair accessible to include: wider doorways, a ramp to the front door, and an accessible bathroom.

The current maximum grant is \$85,645, and a service member or veteran may use the grant three times, up to the maximum dollar amount allowed. To be eligible for the grant, the veteran or service member must be entitled to disability compensation due to:

- Loss or loss of use of both legs: unable to move around without the aid of braces, crutches, canes, or a wheelchair
- Blindness in both eyes, plus loss or loss of use of one leg
- Loss or loss of use of one leg, and residuals of organic disease or injury, or loss or loss of use of one arm, affecting balance and ability to move without aid
- Loss or loss of use of both arms at or above the elbows
- Severe burn injury

PVA's Position

- PVA supports legislation that would allow VA to prioritize a veteran's SAH claim if the veteran has been diagnosed with a terminal illness, including Amyotrophic Lateral Sclerosis (ALS). Due to the aggressive nature of ALS, it is imperative that these veterans are afforded the opportunity for an increased quality of life while they still have the ability to enjoy it.
- PVA supports legislation that increases the amount of the SAH grant to better match the current construction cost.
- PVA supports legislation that would establish a supplementary grant to allow a veteran to modify a different residence if a veteran needs to relocate or if his or her disability worsens. Veterans should not be forced to forfeit opportunities or remain in residences that limit their independence because they are unable to afford to make necessary modifications.



RESOURCES AND ELIGIBILITY FOR THE VA COMPREHENSIVE CAREGIVER PROGRAM

The Issue

On June 6, 2018, President Trump signed into law the VA MISSION Act, authorizing the expansion of eligibility to the Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (Caregiver Program) to those injured before September 11, 2001. Since the program began in 2010, it has been restricted to veterans injured on or after 9/11. Upon verification of the program's Information Technology system, expected October 2019, the program will first be open to those veterans catastrophically injured in service on or before May 7, 1975. Two years from the day of that expansion, those injured in service during any era will be eligible to apply. This will finally correct a shameful inequity that has gone on for too long, and asked caregivers and veterans to endure far too much.

Caregivers are the most important component of rehabilitation and eventual recovery for veterans with catastrophic injuries. Their well-being directly impacts the care veterans receive. The quick and efficient implementation of this program's expansion is critical to ensuring veterans' quality of life. The program currently provides respite care, a monthly stipend, paid travel expenses to attend veterans' medical appointments, and health care through CHAMPVA. Without these services, caregivers are likely to exhaust their savings, experience burnout, or suffer their own injury or illness. This means the veteran is more likely to be placed in an institutional setting that is far more costly to the taxpayer.

As the largest cohort of veterans (Vietnam era) ages, the demand for long-term care resources will continue to grow significantly. By providing their caregivers the means to care for them at home, with family, they will live more fulfilling lives while also delaying the costs of institutional care. That is why PVA urges Congress to properly resource the Caregiver Program and to pass legislation that would also open eligibility to those veterans whose catastrophic illnesses are a result of service. Additionally, Congress must make the stipend eligible for income credits for the purpose of Social Security, so as to not endanger the financial well-being of those caregivers who may spend their lives in such a role.

PVA's Position

- Congress must pass legislation to make veterans with service-connected illnesses eligible to access VA's Caregiver Program.
- VA must request and Congress must provide sufficient funding for VA's Caregiver Program within the VA's medical services' appropriations.
- Congress must pass legislation to allow primary caregivers to earn income credits for their caregiving work, in order to safeguard their own income security.



VA's LONG-TERM SERVICES AND SUPPORTS

The Issue

Long-Term Services and Supports (LTSS) provided through the Department of Veterans Affairs (VA) make up a broad range of assistance to veterans who need help with activities of daily living, as well as instrumental activities of daily living, in a variety of settings, including in the home, assisted living and supportive housing, and nursing homes. As the largest cohort of veterans (Vietnam era) ages, the demand for these services is growing. According to the Veterans Health Administration (VHA), in 2030, the number of veterans with severe disabilities and the number of veterans age 85+ will be more than one million. Women veterans age 65 and older will increase by 73 percent within the decade. Increased VHA enrollment of women veterans coupled with longer life expectancy for women indicates a coming rise in demand for VA geriatric settings for older women that are not currently available. The current LTSS model is limited in its ability to meet the coming needs, both in availability of services and geographic presence.

The majority of LTSS are part of VA's health benefits package and available to all enrolled veterans. In 2006, in an effort to keep veterans supported in their homes, VA began moving away from nursing home care to more cost-effective and preferred Home and Community-Based Services (HCBS). In 2008, VA introduced Medical Foster Homes and Veteran-Directed HCBS, in partnership with the Department of Health and Human Services. From Fiscal Years 2008 to 2017, the proportion of VA's LTSS budget spent on HCBS has risen from 15 to 36 percent.

Despite these efforts, more must be done. PVA is particularly concerned about the availability of VA LTSS for the growing population of veterans aging with spinal cord injuries and disorders (SCI/D). We are concerned that VA is not devoting sufficient resources to meet the demands associated with onset of secondary illnesses and complications associated with aging. VA leadership must commit to balancing the LTSS system, guiding the effort with the VISNs, and providing an evidence-based assessment to be utilized at the facility level that can properly determine the true need of a veteran and caregiver for HCBS. While HCBS is vital and must be more widely available, these services are not a substitution for the need for increased capacity in VA extended care facilities. For example, VA operates only six designated extended care facilities for veterans with SCI/D. Given the size of the aging veteran population and the range of needs, VA must both increase HCBS and increase its bed capacity in institutional settings for these veterans.

PVA's Position

- VA must commit to balancing its LTSS system, while maintaining a safe margin of extended care facility capacity.
- Congress must conduct proper oversight and ensure sufficient funding for VA to appropriately meet all LTSS needs, including for SCI/D veterans living in their homes and those who need SCI/D extended care centers.



Rehabilitation and Prosthetic Services (Automobile Allowance and Adaptive Equipment)

The Issue

Veterans and service members with certain service-connected disabilities are eligible for a one-time only payment of not more than \$21,058.69 to be used towards the purchase of a specially equipped vehicle. Eligibility requirements include:

- Loss, or permanent loss of use, of one or both feet, or
- Loss, or permanent loss of use, of one or both hands, or
- Permanent decreased vision in both eyes: 20/200 vision or less in your better eye with glasses, or greater than 20/200 vision but with a visual field defect that has reduced your peripheral vision to 20 degrees or less in your better eye, or
- A severe burn injury, or
- Amyotrophic Lateral Sclerosis (ALS), or
- Ankylosis in one or both knees or hips (**Note:** This qualifies you for an adaptive-equipment grant only)

VA also provides assistance to service-connected veterans with certain disabilities in adapting no more than two vehicles every four years through the Automobile Adaptive Equipment (AAE) grant. Adapted equipment available to these veterans includes power steering, power windows, power seats, and other equipment needed to operate a vehicle or for ingress or egress. Veterans are required to submit receipts for this equipment to be reimbursed.

Veterans with non-service-connected disabilities are not eligible for AAE. They may be reimbursed, however, for ingress or egress modifications to a vehicle they have purchased. The modifications are paid for out of medical services funding because the purpose of the modifications are to provide the veteran with transportation to medical care.

PVA's Position

- PVA supports legislation allowing veterans to utilize the automobile grant more than once for the purchase, not lease, of an adapted vehicle. Considering vehicles do not last a person's lifetime, veterans should have the ability to purchase a vehicle, with the assistance of the automobile grant, once every ten years, without having to shoulder the burden of the full cost of a vehicle.
- PVA opposes VA requiring veterans to provide an itemized list of "options" included in the price of the vehicle in order to receive the AAE grant. With vehicles being so advanced, many features that were previously categorized as being added equipment, for example, power steering, air conditioning, power windows, and power brakes, are now categorized as standard equipment. Veterans and service members should not have to submit an itemized list of this equipment to qualify for the benefit.
- PVA supports legislation to allow veterans who have non-service-connected spinal cord injuries or disorders to receive the same type of adaptive automobile equipment as veterans whose injuries are service connected.



IMPROVING ACCESS TO AIR TRAVEL

The Issue

Over 30 years ago, President Ronald Reagan signed the Air Carrier Access Act (ACAA) into law. The ACAA prohibits discrimination based on disability in air travel. Despite progress, too many travelers with disabilities still encounter significant barriers, such as damaged assistive devices, delayed assistance, and lack of seating accommodations. Access for people with disabilities must move into the 21st century to ensure that all are able to compete in today's job market and enjoy opportunities available to other Americans.

To address disability-related complaints under the ACAA, passengers with disabilities may file a complaint with the specific airline or the Department of Transportation (DOT). In 2016, passengers filed 32,445 disability-related complaints as reported by 184 domestic and foreign air carriers, which represents a nearly five percent increase over 2015. Top complaints with U.S. carriers for passengers with paraplegia or quadriplegia include failure to provide passenger assistance and appropriate seating accommodations. That same year, passengers also filed 862 disability-related complaints directly with DOT.

Many of the difficulties that travelers with disabilities encounter in air travel are not sufficiently addressed by the ACAA and its implementing regulations. Damaged assistive devices, inadequate training for airline and contractor personnel, and inaccessible airplanes result in missed flights, injuries, and delays that lead to lost time and missed opportunities for people with disabilities. Enforcement of ACAA protections is limited to administrative action and civil fines. Unlike most other civil rights laws, the ACAA lacks a guaranteed private right of action, which means people with disabilities receive limited redress of their grievances.

PVA's Position

Congress must pass legislation that will address these problems by:

- Strengthening ACAA enforcement by requiring referral of certain passenger-filed complaints to the Department of Justice and establishment of a private right of action.
- Ensuring new airplanes are designed to accommodate the needs of people with disabilities by requiring airlines to meet defined accessibility standards. These standards will address safe and effective boarding and deplaning, visually accessible announcements, seating accommodations, lavatories, and better stowage options for assistive devices.
- Requiring removal of access barriers on existing airplanes to the extent that it is readily achievable – easily accomplishable and may be done without much difficulty or expense.
- Improving the overall safety of air travel for passengers with disabilities.



PROVISION OF IVF

The Issue

In September 2016, Congress granted a temporary authorization for the Department of Veterans Affairs (VA) to provide in-vitro fertilization (IVF) to veterans with a service-connected condition that prevents the conception of a pregnancy. On January 19, 2017, IVF services became available through VA. In September 2018, the services were reauthorized for another two years. Constant reauthorization will be required until Congress makes the provision of IVF a permanent VA service. The uncertainty of reauthorization every two years is disruptive to the family and their financial planning. Should the authorization lapse, the ban on VA providing such assistance would be reinstated.

From 2001 to 2013, over 2,000 service members suffered a genitourinary injury, resulting in the loss of, or compromised ability, to have a child. While the Department of Defense does provide reproductive services to service members and retired service members, VA is prohibited from doing so. Since age is a factor in successful fertilization and completion of a pregnancy, delaying the provision of IVF services can have a negative effect on a veteran's success in building a family.

No group of veterans is more affected by the ban on IVF than PVA's members, who are veterans with spinal cord injuries or disorders. PVA has long sought an end to the VA ban on providing IVF. Permanently providing procreative services through VA would ensure that these veterans are able to have a full quality of life that would otherwise be denied to them as a result of their military service. Congress must pass legislation to repeal the ban on IVF and make such services a permanent part of the medical benefits package at VA. Congress has a moral obligation to restore to veterans what has been lost in service, to the fullest extent possible.

PVA's Position

- Congress must pass legislation to repeal the ban on IVF and make such services a permanent part of the medical benefits package at VA.
- Congress must authorize veterans to use donated genetic material and surrogacy in instances where their injuries prevent their ability to contribute sperm or eggs or carry a pregnancy.