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PROTECTION OF SPECIALIZED SERVICES, TO INCLUDE REINSTATEMENT OF ANNUAL CAPACITY REPORT

The Issue

The VA is the best health care provider for veterans. The VA's specialized services, to include spinal cord injury care, most often cannot be duplicated in the private sector. However, these services are expensive and threatened by cost-cutting measures. Even with VA's advances as a health care provider, some political leaders continue to advocate providing health care to veterans by contracting for services in the community. This would move veterans out of the "veteran-specific" care within VA, lead to a diminution of existing services, and increase health care costs in the federal budget.

Further, the critical mass of patients needed to keep all services viable could significantly decline. All primary care support services are critical to the broader specialized care programs provided to veterans. If primary care services decline, then specialized care is also diminished. Specialized services, such as spinal cord injury care, are part of the core mission and responsibility of the VA.

While a great deal of attention has been focused recently on reforming the delivery of veterans health care, much of that discussion has not fully considered the specialized health care needs of veterans with catastrophic disabilities, particularly spinal cord injury or disease (SCI/D). PVA members often travel farther than any of the other population of veterans served by VA. It is not unusual for PVA members, and other veterans with (SCI/D), to travel hundreds of miles to reach one of the 25 spinal cord injury centers located around the country. They do this because the VA SCI system of care is far and away the best option they have. The access problems these veterans face are usually not wait times or distance, but the cost of travel. As a result, veterans may wait to be seen until their condition deteriorates, requiring more costly and intensive care. Congress should expand travel benefits to include non-service connected, catastrophically disabled veterans, who are already granted higher priority, to ensure they are able to receive timely, quality specialty care.

The provision of specialized services is vital to maintaining a viable VA health care system. However, the VA has not maintained its capacity to provide for the unique health care needs of severely disabled veterans. Reductions in both inpatient beds and staff in VA's acute and extended care settings have been continuously reported throughout the system of care, particularly since the capacity reporting requirement expired in 2008. Congress must ensure VA is able to maintain its capacity to provide for the special treatment and rehabilitative needs of veterans. With this in mind, we encourage Congress to consider legislation that will reinstate the capacity reporting requirement originally established by P.L. 104-262, the "Veterans' Health Care Eligibility Reform Act of 1996."

- Congress should enact legislation providing travel reimbursement for veterans with non-service connected, catastrophic disabilities.
- * Congress must reinstate an annual capacity reporting requirement, without a specific end date, for the Department of Veterans Affairs to maintain its ability to provide for the unique health care needs of severely disabled veterans—veterans with spinal cord injury/disease, blindness, amputations and mental illness—as originally mandated by P.L. 104-262.
- Congressional oversight is needed to ensure that the Department of Veterans Affairs is meeting capacity requirements within the recognized specialized systems of care.



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EXPAND ELIGIBILITY FOR THE VA COMPREHENSIVE CAREGIVER PROGRAM

The Issue

The current VA Comprehensive Family Caregiver Program is only available to a veteran seriously injured due to their military service on or after September 11, 2001. Congress should eliminate the unjust date of injury requirement and include "service connected illness" as a criterion for the program. Doing so will give the majority of veterans' caregivers access to critically needed support services.

Caregivers are the most important component of rehabilitation and eventual recovery for veterans with catastrophic injuries. Their well-being directly impacts the quality of care veterans receive. No reasonable justification, other than cost considerations, can be provided as to why pre-9/11 veterans with a service-connected injury or illness should be excluded from the caregiver program.

The caregiver program includes respite care, a monthly stipend, paid travel expenses to attend veteran's medical appointments, and healthcare through CHAMPVA. Without these support services the quality of care provided by the caregiver is threatened and the veteran is more likely to be placed in a costly institutional setting. Both the exclusion of "serious illnesses and diseases," and the use of the "date of injury" as eligibility requirements for such an important benefit are unjust. As a result, the veteran and their family suffer.

As the largest cohort of veterans (Vietnam era) ages, the demand for long term care resources will continue to grow significantly. Catastrophically injured veterans will require the most intensive and expensive institutional care. By providing their caregivers the means to care for them at home with family, they will have the opportunity to live a more normal life while also delaying the costs of institutional care. PVA urges the Senate to pass S. 1085, the "Military and Veteran Caregiver Services Improvement Act" and H.R. 2894, the "Care for All Veterans Act," legislation that would expand access to veterans injured before September 11, 2001.

PVA's Position:

 Congress should pass S. 1085, the "Military and Veteran Caregiver Services Improvement Act" and H.R. 2894, the "Care for All Veterans Act."



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SENIORS AND VETERANS EMERGENCY (SAVE) BENEFITS ACT

The Issue

Veterans with service-connected disabilities and low-income veterans will see no increase in their compensation and pension benefits in 2016 because the Social Security Administration (SSA) announced last October that there would be no cost-of-living adjustment (COLA) in retirement, survivors and disability benefits this year. For many years, veterans' service-connected disability compensation and low-income veterans' pension benefits have been tied to the Social Security COLA. As a result, when SSA offers no inflation adjustment to beneficiaries, this has an adverse impact on over 4 million veterans with service-connected disabilities and another 300,000 low-income veterans on pension.

The "Seniors and Veterans Emergency (SAVE) Benefits Act" (S. 2251 in the Senate and H.R. 4144 in the House), would provide a one-time payment of \$550 to Social Security beneficiaries as well as veteran recipients of compensation and pension to address the lack of inflation adjustment in benefits this year. More than 1 out of 5 adult Social Security beneficiaries have served in the military, and veterans and their families comprise 35 percent of the Social Security beneficiary population. At a time when health care costs, utilities, and many other necessary expenses continue to rise, this very modest provision will help millions of veterans with disabilities and their families.

PVA's Position:

 PVA supports the Seniors and Veterans Emergency (SAVE) Benefits Act, (S. 2251 in the Senate and H.R. 4144 in the House). We urge Members of Congress to cosponsor this legislation and act quickly on its passage.



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IMPROVE BENEFICIARY TRAVEL FOR CATASTROPHICALLY DISABLED VETERANS

The Issue

While a great deal of attention has been focused recently on reforming the delivery of veterans health care, much of that discussion has not fully considered the specialized health care needs of veterans with catastrophic disabilities, particularly spinal cord injury or disease (SCI/D). PVA members often travel farther than any other cohort of the veterans' population. It is not unusual for PVA members, and other veterans with (SCI/D), to travel hundreds of miles to reach one of the 25 spinal cord injury centers located around the country. They do this because the VA SCI system of care is far and away the best option they have. The access problems these veterans face are usually not wait times or distance, but the cost of travel. As a result, veterans may avoid traveling to receive care until a minor condition becomes serious or even life-threatening, requiring more costly and intensive care.

Congress should expand beneficiary travel to include non-service connected, catastrophically disabled veterans, who are already granted higher priority, to ensure they are able to receive timely, quality specialty care. While VA will continue to face tighter budgets in the future, the short term costs of expanding this benefit to this population of veterans far outweigh the potentially greater long term health care costs for these veterans. Too often, catastrophically disabled veterans choose not to travel to VA medical centers for appointments and procedures due to significant costs associated with their travel. They end up at an outpatient clinic or a private health care facility that is ill-equipped to meet their specialized health care needs. The result is often the development of far worse health conditions and a higher cost of care. By ensuring that catastrophically disabled veterans are able to travel to the best location to receive necessary care, the overall health care costs to the VA can be reduced.

PVA believes that expanding VA's beneficiary travel benefit to this population of severely disabled veterans will lead to an increasing number of catastrophically disabled veterans receiving quality, timely comprehensive care, and result in long-term cost savings for the VA. Eliminating the burden of transportation costs as a barrier to receiving health care, will improve veterans' overall health and well-being, as well as decrease, if not prevent, future costs associated with exacerbated health conditions due to postponed care.

During the lie Congress, H.R. 288 and S. 171, the "Veterans Medical Access Act" have been introduced to deal with the transportation needs of these low income veterans. In the long run, this will save money for both the veteran and the VA as medical issues can be dealt with early before they become serious.

PVA's Position:

• Congress should pass H.R. 288 and S. 171, the "Veterans Medical Access Act" to expand travel reimbursement benefits to non-service connected catastrophically disabled veterans.



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PROBLEMS WITH DENIAL OF CLOTHING ALLOWANCE FOR CATASTROPHICALLY DISABLED VETERANS

The Issue

Specifically, Paragraph 8a in the Handbook provides guidance for items that tend to wear and tear clothing including manual wheelchairs "without clothing guards...wheelchairs (power, electric) without special modifications are not approved." The implication is that wheelchairs with clothing guards and power chairs without special modifications do not create wear and tear. The VA Clothing Allowance Frequently Asked Questions dated September 30, 2014, confirms the denial. People in wheelchairs can attest that there is more to wear and tear than clothing guards and special modifications. Veterans who go through the daily ordeal of transferring, and whose cuffs and sleeves are soiled by wheels can verify those activities wear and tear their clothes.

The third problem area began with the letter sent by the Veterans Benefits Administration (VBA) in 2014 to inform veterans that they may be eligible for more than one Clothing Allowance. The letter caused confusion among many veterans who filled out a form to apply for more than one Clothing Allowance. The result was veterans who had been on a Static (recurring benefit) status were transferred to a Reapply status. Many of those veterans who had been on a Static status for decades did not realize they had been transferred to Reapply status. Consequently, they did not apply and did not receive their Clothing Allowance benefit for 2014. Those veterans want to be returned to Static status so they do not have to reapply every year and they want to receive the Clothing Allowance benefit they missed as a result of this confusion.

- Congress must ensure that VA rewrites VHA Handbook 1173.15 to provide Clothing Allowance to veterans who have clothing guides on their wheelchairs and veterans who use standard power wheelchairs without modifications.
- Congress must ask VA to restore Static Status to those veterans who have had it for years and to pay them for the year they missed.



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INCLUSION OF PROCREATIVE SERVICES IN VA HEALTH CARE

The Issue

The VA is prohibited from providing assisted reproductive technology, in particular in-vitro fertilization (IVF), to veterans with a service-connected condition that prevents the conception of a child. From 2001 to 2013, over 1,200 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 does not. The reasons for this disparity are purely ideological in nature and overlooks the country's obligation to make severely disabled veterans as whole as possible, which includes providing opportunities to raise a family if he or she so desires.

When a veteran has a loss of reproductive ability due to a service-connected injury, they must bear the total cost for any medical services should they attempt to have children. It is often the case that veterans cannot afford these services and are not able to receive the medical treatment necessary for them to conceive. For many veterans procreative services have been secured in the private sector at great financial and personal cost to the veteran and family.

PVA has long sought an end to the VA ban on providing reproductive services, particularly IVF. Reproductive assistance provided as a health care benefit through VA would ensure that these veterans are able to have the highest quality of life that would otherwise be denied to them as a result of their injury during service. PVA urges the House of Representatives to pass H.R. 2257, legislation that would correct this prohibition once and for all. Similarly, we urge the Senate to pass S. 469, the "Women Veterans and Families Health Services Act." It is Congress that sends young men and women into harm's way. It is Congress that has a moral obligation to restore to veterans what has been lost in service, to the fullest extent possible. And it is Congress that must provide health care services and benefits that address the needs of veterans that result from their service.

PVA's Position:

 PVA urges Congress to pass S. 469, the "Women Veterans and Families Health Services Act of 2015" and H.R. 2257. This legislation would authorize VA to provide veterans with reproductive assistance services.



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AIR CARRIER ACCESS ACT

The Issue

Nearly 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, inaccessible lavatories, delayed assistance, and lack of seating accommodations. Access for people with disabilities in air travel must move into the 21st century. Otherwise, people with disabilities will be left behind unable to compete in today's job market or enjoy the 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 July 2015, DOT released the latest figures on complaints filed directly with airlines. In 2014, passengers filed 27,556 disability-related complaints as reported by 173 domestic and foreign air carriers, which represents a nine percent increase over 2013. Top complaints with U.S. carriers for passengers with paraplegia or quadriplegia include failure to provide assistance, seating accommodation, and storage and delay of assistive device. In 2015, passengers also filed 939 disability-related complaints directly with DOT.

Many of the difficulties that travelers with disabilities encounter in air travel are not sufficiently addressed through the ACAA. For example, DOT regulations do not require airlines to provide accessible lavatories on single aisle aircraft. Additionally, 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. Unlike other civil rights laws, the ACAA also lacks a guaranteed private right of action. Consequently, people with disabilities typically receive little if any redress to their specific grievances.

PVA's Position:

- ACAA enforcement must be strengthened by amending the statute to include specific protections and a private right of action.
- Improved training for air carrier personnel and their contractors must include a focus on industry best practices to close remaining service gaps in air travel for passengers with disabilities.
 Fostering regular communication with stakeholders will also be crucial.

Airplanes must be designed to accommodate people with disabilities and airlines must acquire planes that meet broad accessibility standards. Improved structural access includes accessible lavatories on single aisle aircraft and better stowage options for assistive devices. Establishing design standards will ensure that features are usable for passengers with disabilities.

 Policies and regulations must be reformed to improve access to seating accommodations and remove heightened restrictions for some service animals.



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COMPLEX REHAB TECHNOLOGY RECOGNITION UNDER MEDICARE

The Issue

The Durable Medical Equipment (DME) benefit was created over forty years ago to address the medical equipment needs of the elderly. Over the years available technology has advanced and now includes complex rehab power wheelchairs, highly configurable manual wheelchairs, adaptive seating and positioning systems, and other specialized equipment, such as standing frames and gait trainers. This technology — called Complex Rehab Technology (CRT)— is prescribed and customized to meet the specific medical and functional needs of individuals with disabilities and medical conditions such as, but not limited to, Cerebral Palsy, Muscular Dystrophy, Multiple Sclerosis, Spinal Cord Injury, Amyotrophic Lateral Sclerosis (Lou Gehrig's disease), and Spina Bifida. CRT is used by individuals with serious medical conditions different from the traditional elderly Medicare population. This population group, who tend to qualify for Medicare based on their disability and not their age.

Because the equipment is complex and becomes an extension of the person, fitting, training, and education requires more time than standard DME items. In addition, Medicare requires environmental assessments within the home for some CRT products. The Medicare program requires that Complex Rehab Technology companies employ specialized and credentialed staff to analyze the needs of individuals with disabilities and assist in the selection of the appropriate equipment. These credentialed personnel, called Assistive Technology Professionals (ATP), are certified by the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) and specialize in the assessment, selection and provision of Complex Rehab Technology products.

In 2008, Congress recognized that complex rehab power wheelchairs are unique and more specialized than standard durable medical equipment (DME) and should be treated differently. As a result these items were exempted from inclusion of Medicare's new DME

competitive acquisition program. However a separate CRT recognition structure was not established at that time. CMS has recognized the unique measure of other customized assistive devices and has created a separate and distinct classification for orthotics and prosthetics (O&P) i.e. custom braces and artificial limbs.

- PVA believes a Separate Medicare Complex Rehabilitation Technology (CRT) recognition structure is needed.
- PVA asks that Congress pass H.R.1516/S. 1013 the "Ensuring Access to Quality Complex Rehabilitation Technology Act," a bipartisan bill that will create a separate recognition category for complex rehab technology.



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VETERANS HEALTH CARE REFORM

The Issue

Veterans health care reform will remain a legislative priority in 2016. Our priority is to ensure that these reform efforts guarantee care that is high quality, accessible, comprehensive and veterans-centric. Following implementation of the "Veterans Access, Choice, and Accountability Act of 2014" (the "Choice Act"), the Department of Veterans Affairs (VA) has made progress toward alleviating pervasive and systemic problems. As VA takes its next step, Paralyzed Veterans of America (PVA) has worked with VA officials throughout the development of the new Veterans Choice Program, a plan to consolidate all non-Department provider programs. Many of our key recommendations were incorporated into that plan, such as ensuring through care coordination that VA remains accountable for the care veterans receive, regardless of where that care is delivered. While we in large part support VA's plan for consolidation, we remain committed to certain differences in approach, specifically regarding eligibility determinations.

PVA, and our partners in The Independent Budget, have presented to Congress a framework for bringing high-quality health care closer to home. The framework offers comprehensive policy ideas designed to immediately impact the delivery of care. It also lays out a strategic, long-term vision for a sustainable, high-quality and veteran-focused health care system that we believe veterans have earned and deserve. Our historical expertise and extensive interaction with veterans around the country leads us to confidently conclude that veterans prefer to receive their care from VA. They like the quality of care received, and they believe VA is best suited to provide veteran-specific health care. This is particularly true of veterans with spinal cord injury or disease, as there is not comparable specialized care in the private sector. To ensure that reforms focus on veterans' experience, service delivery, management and accountability, our framework should inform and drive future legislative and regulatory proposals.

- PVA generally supports the VA plan to restructure the system in a way that establishes integrated health
 care networks designed to leverage the capabilities and strengths of existing local resources. This will
 provide more efficient, higher quality and better coordinated care.
- PVA supports a shift in the access eligibility from arbitrary standards to one of clinical need and
 patient/doctor decision-making. We propose removing the arbitrary wait time and distance analysis which is
 non-existent in the private sector.
- PVA supports employing a Quadrennial Veterans Review, similar to the Quadrennial Defense Review. The
 ability to take the long view of prospective personnel and infrastructure resources will offer continuity of
 planning across administrations and better prospects for meeting future demand with sufficient resources.
- PVA supports changing the workforce culture through a holistic approach focused on more than firing
 employees. Strengthening VA's ability to recruit, train and retain quality professionals dedicated to placing
 veterans' interests first is critical to restoring faith in VA.



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Legislative Program Priorities (Veterans Issues)

- 1. Veterans Health Care Reform
 - A joint effort of *The Independent Budget—PVA*, DAV, and VFW.
 - Grounded in the principles that veterans health care should be high-quality, accessible, comprehensive, and veterans centric.
 - Reform plan is built on four pillars: restructure, realign, redesign, and reform.
- 2. Expand Eligibility for the VA Comprehensive Caregiver Program
 - Expand access to the Comprehensive Family Caregiver Program administered by VA to veterans of all eras (not just those injured after September 11, 2001).
 - Should also include veterans with catastrophic illness, such as ALS or MS.
 - PVA urges passage of H.R.2894, the "CARE for All Veterans Act," and S. 1085, the "Military and Veterans Caregiver Services Improvement Act."
- 3. Procreative Services for Catastrophically Disabled Veterans
 - Legislation would allow VA to provide for procreative services, to include in vitro fertilization (IVF), to veterans with catastrophic injuries that preclude them from having children.
 - PVA urges passage of H.R. 2257 and S. 469, the "Women Veterans and Families Health Services Act."
 - 4. Protection of Specialized Services, to Include Reinstatement of Annual Capacity Report
 - VA is the best health care provider for veterans.
 - VA's specialized services, to include spinal cord injury care, most often cannot be duplicated in the private sector.
 - VA has not maintained its capacity to provide for the unique health care needs of severely disabled veterans.
 - PVA urges Congress to pass legislation that will reinstate the annual capacity reporting requirement originally established by P.L. 104-262, the "Veterans' Health Care Eligibility Reform Act of 1996."
 - 5. Problems with Denial of Clothing Allowance for Catastrophically Disabled Veterans
 - VHA Handbook 1173.15 (dated May 14, 2015) has three main flaws.
 - 1. Veterans with wheelchairs that have clothing guides are denied clothing allowance.
 - 2. Standard power wheelchairs without modifications are denied clothing allowance.
 - 3. Confusion over Static versus Reapply provision has caused veterans to lose the benefit.

Advocacy Program Priorities (Disability Issues)

- 1. Air Carrier Access Problems for People with Disabilities
 - Passengers with disabilities, particularly those with significant disabilities, continue to experience a wide array of problems and seemingly discriminatory acts in air travel.
 - The Air Carrier Access Act must be amended and enforced to improve air travel for people with disabilities.
- 2. Complex Rehabilitation Technology.
 - Separate Medicare Complex Rehabilitation Technology (CRT) benefit is needed. CRT is designed to meet the specific and unique medical and functional needs of someone diagnosed with a catastrophic illness or disability.
 - PVA urges Congress to pass H.R. 1516/ S. 1013, the "Ensuring Access to Complex Rehabilitation Technology Act."
- 3. The "Seniors and Veterans Emergency (SAVE) Benefits Act"
 - Veterans with service-connected disabilities and low-income veterans received no cost-of-living adjustment (COLA) in 2016 for their compensation and pension benefits.
 - PVA urges passage of H.R. 4144 and S. 2251, the "Seniors and Veterans Emergency (SAVE) Benefits Act."