Paralyzed Veterans of America

1875 Eye Street NW, Suite 1100,
Washington, DC 20006
(O) 202.872.1300
www.PVA.org

501(C)(3) Veterans Non-Profit

STATEMENT OF JULIE HOWELL

ASSOCIATE LEGISLATIVE DIRECTOR

PARALYZED VETERANS OF AMERICA

BEFORE THE

SENATECOMMITTEE ON VETERANS' AFFAIRS

ON

CARING FOR ALL WHO HAVE BORNE THE BATTLE:
ENSURING EQUITY FOR WOMEN VETERANS AT VA

APRIL 10, 2024

Chairman Tester, Ranking Member Moran, and members of the committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to present our views on ensuring equitable access to care for women veterans. Few veterans understand the full scope of benefits offered by the Department of Veteran Affairs (VA) better than PVA members – veterans who have incurred a spinal cord injury or disorder (SCI/D), including multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS).

While the number of women PVA members is small compared to the rest of the women veteran population, they are an impressive group of individuals who do not allow their disabilities to hinder their efforts to improve access to equitable care for all veterans. Ensuring that women PVA members have timely access to quality care will only help VA to be better positioned to deliver care for all veterans, particularly those with complex injuries and illnesses. Women veterans are the fastest growing veteran cohort using VA benefits and services, accounting for nearly 30 percent of all new VA enrollees. It is our obligation to ensure that women veterans encounter barrier-free access to health care and benefits equal to their male counterparts.

In recent years, women veterans have achieved several legislative wins that are worth celebrating. Bills like the Making Advances in Mammography and Medical Options (MAMMO) Act (P.L. 117-135); the Dr. Kate Hendricks Thomas Supporting Expanded Review for Veterans in Combat Environments Act or the SERVICE Act (P.L. 117-133); the MST Claims Coordination Act, which passed in the Cleland-Dole Act of 2022 (P.L. 117-328); and the Deborah Sampson Act passed in the Isakson-Roe Health Care and Benefits Improvement Act of 2020 (P.L. 116-315), which represented big investments in women veterans' health care. PVA remains grateful to Congress for passing these important bills, but our work is far from over.

We appreciate the opportunity to share our views on the current state of care for women veterans because we believe increased attention is necessary to ensure we are meeting their needs. However, women veterans are veterans, so almost every piece of veterans-related legislation that Congress passes will impact them. Women veterans are served by the Veterans Benefits Administration (VBA), the Veterans Health Administration (VHA), and the National Cemetery Administration (NCA) just like their male counterparts. We do women veterans a disservice whenever we fail to consider how all legislation related to these administrations impacts them.

PVA Priorities for Women Veterans with SCI/D

There are several areas of concern for PVA regarding VA's support for our women members. Due to the types of injuries and illnesses that our members live with, their needs are often unique compared to other veterans with disabilities. In our testimony, PVA would like to highlight a few provisions within the Deborah Sampson Act that could be improved, discuss accessibility for gender-specific health care, including mental health supports, as well as limitations for women accessing long-term care, and the need for increased gender-specific research focused on aging women veterans with SCI/D.

Improvements to the Deborah Sampson Act

The Deborah Sampson Act (DSA) was a major achievement because it raised awareness of the deficiencies that women veterans encountered across the VA and forced the department to prioritize women veterans' health care. Three years following its passage, however, our women members report seeing little impact or improvement in their engagements with the VA. Below are a few areas from the law that merit further attention.

Section 5102 of the DSA appropriated $20 million for the VA to retrofit their facilities to better accommodate women veteran care. This section prioritized "fixtures, materials, and other outfitting measures to support the provisions of care to women veterans." Progress has been made in the delivery of care for women veterans, that cannot be denied. However, we hear from our women members regularly that even updated women's health clinics or specialty areas within VHA facilities still lack basic accessibility measures.

Section 5104 of the DSA outlines provisions for reintegration and readjustment services to veterans in group retreat settings provided by VA Vet Centers. Many women veterans have benefited from these retreats, receiving care and camaraderie in safe spaces to discuss their concerns and struggles among their fellow veterans. Unbeknownst to most people, however, is that if a woman veteran uses a wheelchair and/or has additional nursing needs, they are unable to access these transformative retreats. In fact, there is no facility within VHA that allows for residential treatment of any kind for women or male veterans with additional nursing needs. In various briefings offered by VA, PVA has inquired about the locations that offer residential care for catastrophically disabled veterans, which the VA claims exist, but the department has yet to provide them to us.

Section 5108 highlights the need for gender-specific prosthetics for women veterans. Prosthetic devices include more tools and supports than most people think, and VA offers a range of gender-specific prosthetics such as intrauterine devices (IUDs), mobility aids, maternal support equipment, communication and assistive devices, and many other items intended to improve the quality of life for

a veteran. However, PVA has seen disparities when it comes to the availability of critical prosthetic devices, such as gender-specific catheters. For veterans that require catheterization, these are necessary, life-saving devices that when ill-fitting, have the potential to cause lasting harm.

Section 5110 requires a study on infertility services furnished by the VA. PVA has long championed the expansion of assisted reproductive technology (ART) offered by the VA, particularly increased access to in vitro fertilization (IVF). While IVF has gained national attention in recent weeks and months, and as the VA is set to expand access to IVF services for some veterans, we still lack data on the number of veterans applying for IVF, how many veterans are being denied access to these services, and for what reason are they being denied. The report required by section 5110 is critical to understanding the needs of veterans who struggle with infertility.

Section 5502 allows a veteran filing a compensation and pension (C&P) exam related to military sexual trauma (MST) to choose the gender of their provider, affording the veteran the highest level of comfort during this difficult process. MST is a pervasive issue within the military and veteran community and for veterans that are brave enough to come forward the VA needs to be prepared to support them. While the DSA mandated that a veteran could choose the gender of their provider, our national service officers (NSOs) report that this option is not being offered to the women veterans they assist. Several women filing claims have reported that the male providers they were assigned for their C&P exams came across as cold, rude, and short. If we continue to say that the VBA is the doorway to the VA, how can we expect women veterans to feel welcome when at their initial examination they feel disrespected and disparaged?

Additionally, when it comes to C&P exams ordered by the VA, our NSOs have run into complications in accessing obstetrician gynecologists (OBGYN) for reproductive exams. VA should classify reproductive exams as a specialty appointment to ensure women veterans are meeting with the appropriate health care providers when engaging with C&P examiners, which would help ensure another level of gender-specific care and a quality exam.

Veterans service organizations (VSO) are eagerly awaiting the release of all reports mandated in the DSA because the data they will contain is critical in understanding the effectiveness of the Act. Without this information, we are incapable of assessing what is working and what is not. It was recently brought to our attention that a provision within the fiscal year (FY) 2022 National Defense Authorization Act (P.L. 117-263) required all congressionally mandated reports (CMR) to be published to a website managed by the Government Printing Office. The Office of Management and Budget published its guidance for this new rule in June of 2023,[1] but none of the CMRs from the DSA or any other piece of legislation have been published to this central website. We urge Congress to ensure that all CMRs are posted in a timely manner so that external stakeholders can conduct their necessary oversight.

Accessibility for Gender-Specific Care

Most of our members receive much of their care within the VA's SCI/D system of care, which provides a coordinated life-long continuum of services for veterans and is the only such system in the world.

[1] Executive Office of the President, Office of Management and Budget, June 2023.

This unique care system provides services and supports from the time of injury and acute care needs, through the life of the veteran. While the VA's SCI/D system is truly remarkable, there are still concerns for PVA when it comes to accessing care for our women veterans.

Our women members often report that it is difficult to access gender-specific care within the SCI/D system because it requires a high level of cooperation and coordination with the women's health clinics. With limited staff inside women's clinics, there is often difficulty in coordinating this care. It is left up to each facility to proactively establish integrated care for patients within the SCI/D system, and unfortunately, this has not been a priority for many locations.

One PVA leader shared that OBGYN services have only been available at her VA for four years. The only way to access them is through a consult from her primary care provider at the SCI/D center and the women's health clinic, which is sometimes difficult to arrange. Many women veterans receive their primary care through a women's health clinic which eliminates this extra step in accessing their care. She goes on to share there are no other accessible clinics to receive GYN services. Often when providers are made available to the SCI/D clinic, they are general practitioners and unable to answer patient questions. She said the process is, "very embarrassing and it makes you feel second-class."

Many PVA members also share that their women's clinic is not physically accessible to them. As the VA works to fulfill their requirements for the retrofit initiative for women's health, accessibility should be a priority, but it is not. Accessibility goes beyond parking spaces and automatic doors.

In a recent survey, PVA's women leaders were asked about physical accessibility when it comes to receiving gender-specific care. One respondent provided that her experience at the VA includes small exam rooms; inadequate exam tables; a lack of family bathrooms, which are often preferred by our members because of the additional space, and if needed, to accommodate a caregiver of a different gender; an inability to get into some clinic doors; and a lack of general accessibility, starting in the parking lot and continuing to the exam rooms. We also hear from our members that many women's health clinics lack ceiling lifts, which are necessary for the safety of veterans in transferring to and from their wheelchairs. Accessibility concerns were the main driver for PVA to engage in the drafting and passage of the MAMMO Act. PVA is eagerly awaiting the release of VA's study on the accessibility of breast imaging services since we still see many of our women members being sent into the community for this service.

PVA would like to highlight one bill in particular that could help address several accessibility concerns within the VA. S. 2516, the Veteran Accessibility Act, would establish an Advisory Committee that would focus on improving accessibility to VA facilities and electronic information sources. It would also review barriers to health care at VA facilities and its community care providers. Lastly, the bill requires the Committee to ensure the acquisition process will result in the VA receiving products, services, and equipment that meet accessibility requirements. Accessibility needed due to veterans' disabilities should be a priority for the VA; however, we see time and time again that SCI/D veterans often run into architectural barriers, inaccessible medical diagnostic equipment, and technology barriers. Federal laws exist to protect disabled veterans; however, issues persist. We urge Congress to pass S. 2516 to ensure the VA prioritizes accessibility for our disabled veterans.

Access to Long-Term Services and Supports

In his testimony to the Veterans' Affairs Committees on March 6, PVA National President Robert Thomas stressed the need for increased access to long-term services and supports. The lack of adequate long-term care options is a nationwide problem, and if the VA is planning on relying on community care to help with the lack of facility-based beds, many veterans are going to be left behind, particularly veterans with catastrophic disabilities.

The VA operates six facilities that have long-term care beds to serve veterans with SCI/D, but only one of those facilities is west of the Mississippi. All totaled, the VA is required to maintain 198 authorized long-term care beds at SCI/D centers to include 181 operating beds. As of February, only 169 beds were available. This is a variable number, dependent on staffing, isolation precautions, and if there are women veterans admitted for long-term care. When averaged across the country, that equates to about 3.4 available beds per state.

In 2021, construction began to replace an acute SCI/D center in San Diego which will update the 30 acute care beds, many shifting into single occupancy rooms, and add 20 new long-term care beds to the system, but this project isn't projected for completion until 2025. Additionally, there is a new long-term care SCI/D center at the VA North Texas health Care System in Dallas which broke ground in January of 2024. This location will include 26 SCI/D, single occupancy rooms, along with two double occupancy rooms. The project is expected to be completed in 2027. Phase two of the Dallas project would add an additional 28 long-term care rooms (26 single occupancy, two double occupancy), however, phase two of the Dallas project has not been funded. Also, existing VA rules require that space to remain incomplete for a year before construction can begin.

Although applicable to all PVA members, it's crucial to mention these infrastructure projects when it comes to discussions around women veterans. We currently have a woman member in need of a long-term care bed in New York. The SCI/D center she is in reached out to several nearby VA community living centers, but none of them have available beds for female veterans. Thus, she is forced to remain in an SCI/D acute center until a bed becomes available that can provide the level of care she needs.

Long-term care services are expensive, with institutional care costs exceeding costs for home and community-based services (HCBS). Studies have shown that expanding HCBS entails a short-term increase in spending followed by a slower rate of institutional spending and overall long-term care cost containment.[2] Because of the preference of PVA members to live at home and the financial benefits shown by studies like these, PVA supports swift passage of the Elizabeth Dole Home Care Act (H.R. 542/S. 141), which would make critically needed improvements to VA HCBS. We cannot stress enough how disappointed our members are that this legislation still has not passed into law.

Even once HCBS programs are available to veterans, the challenges of receiving proper home care assistance continue. Anne Robinson, PVA National Vice President and Army veteran, was injured in a military vehicle accident in October 1999 that left her as a quadriplegic. Her husband, Harry, has been her primary caregiver but Anne's physical needs are significant, and they must rely on direct care

[2] Do noninstitutional long-term care services reduce Medicaid spending?

workers to provide the level of care Anne requires.[3] Finding a candidate who understands the unique needs of this work has been difficult for Anne and Harry. They have interviewed more than 100 applicants to help provide this critical care, but few have lasted more than a handful of months due to the limited pay authorized through the Veteran Directed Care program and the complexity of her care needs. Anne not only lives with complex SCI/D but now she has been burdened with the realities of the direct care worker shortage.

The shortage of caregivers or direct care workers is not unique to the VA. Across the country, there is an increasing shortage of direct care workers, and a national effort is needed to expand and strengthen this workforce. I share these stories to emphasize how precarious the HCBS/long-term care system is and how the lack of home care providers is adversely impacting the care and quality of-life of veterans with SCI/D. Veterans with disabilities have the right to quality care in their homes.

Research Focused on Women Veterans with SCI/D

The increased focus on women's health research at the VA is essential in understanding the needs of our women veterans. However, research for veterans with SCI/D in general is lacking, and this is particularly true when it comes to women veterans with SCI/D. The VA's century-long history of improving the lives of veterans and other Americans through medical and prosthetics research positions them well to conduct studies focusing on these vulnerable populations.

The passage of the Honoring our PACT Act (P.L. 117-168) has been center stage for much of the marketing and focus coming from the VA and Congress in recent years. However, we need additional research into toxic exposures and how they may have uniquely impacted women veterans. Initial data published in the American Journal of Obstetrics and Gynecology, shows an association between environmental, chemical, and hazardous materials and infertility, which was supported by work done by VA Health Services Research and Development Service (HSR&D) researchers.[4] PVA encourages the VA to increase its efforts in women's health research so that the VA is prepared and educated about the unique experiences of women veterans that affect fertility.

Thanks to medical advancements, increased regulation, and improved safety measures, veterans with SCI/D are living longer than ever. This means that as the timeline of care increases, veterans are sure to experience increased care needs, and comprehensive understanding about aging will be critical in supporting these veterans. Only recently have research efforts been focused on what it means to age as a woman and that body of knowledge is limited, particularly for women veterans with catastrophic disabilities. This becomes a critical data point when one realizes the average age for a woman veteran enrolled in VA health care is 55-62.

SCI/D veterans are no different from their ambulatory counterparts when it comes to aging. Their injury does not change the reality that they'll age into the same biological aging disabilities as their peers such as decreased muscle mass, cognitive decline, and osteoporosis. However, for a veteran with SCI/D, these conditions may be exacerbated due to the limited function of their aging body.

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[3] PVA.com, Caregiver Support

[4] Lifetime infertility and environmental, chemical, and hazardous exposers among female & male US veterans, November 2022.

Existing literature focused on people aging with SCI/Ds discusses the complications that can arise from SCI/D and the treatments that exist to combat them. Anyone aging with an SCI/D is likely to see complications in the musculoskeletal system, as well as the endocrine (glands) and cardiovascular systems. They are also more likely than those without SCI/Ds to have bone density loss, chronic pain, pressure injuries, and kidney and bladder stones. Preliminary research also shows an increased risk of developing dementia when someone lives with an SCI/D, meaning that the aging challenges likely to be encountered by our women members are going to be dynamic[5].

We know that women with MS run into challenges with aging that are unique to their medical needs. Women are twice as likely as men to be diagnosed with MS. Research highlights that disability associated with MS tends to worsen around the fifth decade, meaning that our women veterans with the disease face unique challenges that the VA needs to be prepared to react to and ready to treat. Many advances have been made in treating MS including improved disease-modifying therapies, however, research shows that women with it are prone to adverse effects of these treatments, as they age. Research also shows that for aging women with MS, the "age-related decline in physical health is accelerated by 15-30 years compared to their unaffected peers"[6].

PVA members are already living with catastrophic disabilities. As time goes on, those disabilities will be exacerbated, and eventually, they will experience the inevitable biological disabilities that come with aging. The comorbidities they are likely to encounter as aging veterans with SCI/D are under researched, leaving many veterans unsure of what to expect in the coming years, and this is particularly true of our women veterans. PVA commends the efforts the VA has made around gender-specific research, particularly within the HSR&D and the VA Women's Health Research Network. The SCI/D system should work in coordination with HSR&D to advance the impressive body of research already possessed by the VA, particularly around women veterans.

Cultural Competency on Women with SCI/D and MST

The national dialogue around sexual trauma and standards of behavior has changed drastically over the past twenty years. As more and more individuals come forward to share their experiences, veterans and servicemembers are also speaking out. Per the Department of Defense's (DOD) Annual Report on Sexual Assault for FY 2022,[7] 8.4 percent of active-duty women, and 1.5 percent of active-duty men experienced unwanted sexual contact. This accounts for nearly 36,000 servicemembers, many of whom might seek benefits and services from the VA.

In January of this year, research was published that analyzed MST claims ratings from October 2017-May 2022. From that five-year period, an estimated 27.5 percent of claims were denied, especially when compared to combat-related PTSD claims which were only denied at the rate of 18.2 percent.[8]

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[5] Characteristics of Women Veterans with Dementia: Care Report and Review of the Study of Health of Vietnam-Era Women's Study, April 2024.

[6] Impact of aging on treatment considerations for multiple sclerosis patients, July 2023.

[7] Department of Defense Annual Report on Sexual Assault in the Military, FY2022.

[8] Military sexual trauma-related posttraumatic stress disorder service connection: Characteristics of claimants and award denial across gender, race, and combat trauma, January 2024

The denial rate becomes even greater for women of color and male veterans. The number of veterans living with a history of MST is significant and yet they are still encountering challenges when filing claims with VBA.

Long-range symptoms of MST that a veteran can use to justify their claims include things like "sexual difficulties; chronic pain, weight or eating problems, gastrointestinal problems," as well as physical pain in affected areas of the body.[9] Often veterans are unable to grapple with their MST until years, sometimes decades, later. In a 2021 survey of PVA's women members, nearly 40 percent of the respondents had experienced MST in service and many PVA members are finally filing MST claims 20 or 30 years after the incident. However, for several of our SCI/D veterans, due to their injuries, some of the physical long-range symptoms of MST are incapable of manifesting. This doesn't make their experience and trauma any less real.

The VA has made strides toward increasing the accuracy of MST claims in the past several years. Multiple VA Office of Inspector General (OIG) reports have underscored VBA's incremental improvements around the processing of these claims. However, a few percentage points in an OIG report still represents thousands of veterans. Due to the continued challenges with MST claims decisions, PVA recommends Congress pass S. 1028, the Servicemembers and Veterans Empowerment and Support Act of 2023, which aims to expand the evidentiary standard for survivors applying for disability benefits from the VA to ensure MST survivors are provided equal access to benefits and care.

IVF Efforts and Infertility

PVA has long championed increasing access to ART, particularly access to IVF. Recently, the VA and the DOD, announced expanding access to IVF services for some servicemembers and covered veterans. We commend the agencies in removing the marriage requirement along with the previous prohibition on donated genetic material. VA's proposed changes went into effect on March 28, and while it is an important victory, they will only impact a small number of veterans.

PVA strongly supports S. 2801, the Veteran Families Health Services Act of 2023, which seeks to alleviate issues servicemembers and veterans face when trying to receive fertility treatment. The bill would expand VA and DOD fertility treatments and ensure they offer comprehensive family-building assistance for veterans and servicemembers. Also, it creates proactive fertility cryopreservation procedures which will help if a veteran or servicemember faces an illness or injury. If passed, the bill would also increase adoption assistance for a veteran that has a proven infertility diagnosis.

Collaboration with Other Stakeholders

The committee expressed interest in learning more about the work of the VSO Women Veteran Working Group. PVA is fortunate to work with several coalitions focused on increasing awareness, equity, and resources for veterans and all people with disabilities. The working group creates an environment to facilitate discussion about the various needs of our memberships, review legislation, and identify areas of concern and possible solutions. We also work with Congress and the VA to review

[9] Military Sexual Trauma Fact Sheet; Department of Veterans Affairs

data to gauge the effectiveness of policy and we invite subject matter experts to share with us, particularly in the areas of women veteran research.

Now that several iterations of the House's Women Veteran Task Force have completed their work, and subsequent united call for additional support from Congress, we are pleased that there is now a bipartisan, bicameral discussion with organizations on women veterans open to all VSOs. We are hopeful that these conversations will provide space for further discussions around women veterans and that policy solutions will arise from this collaboration.

PVA would like to thank the committee for allowing us the opportunity to share the unique needs of our women members. Our members are almost exclusively reliant on the VA for their health care, benefits, and ultimately, their independence. Ensuring that the VA works for the most vulnerable veterans does not take away from other veterans, rather it guarantees that the VA can serve all the veterans they are obligated to provide care for. PVA is happy to answer any questions the committee may have.