STATEMENT FOR THE RECORD

PARALYZED VETERANS OF AMERICA

FOR THE

HOUSE COMMITTEE ON VETERANS' AFFAIRS

SUBCOMMITTEE ON HEALTH

AND THE WOMEN VETERANS TASK FORCE

ON "BEYOND DEBORAH SAMPSON: IMPROVING HEALTHCARE FOR AMERICA'S WOMEN VETERANS IN THE 117TH CONGRESS"

MARCH 18, 2021

Chairwoman Brownley, Ranking Member Bergman, and members of the Subcommittee and Task Force, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit our views on improving health care for women veterans. PVA's members are all veterans with spinal cord injuries or disorders (SCI/D), including multiple sclerosis (MS) and amyotrophic lateral sclerosis. The vast majority of PVA's members depend on the Department of Veterans Affairs (VA) for a significant part of their care. Thus, VA's ability to meet the unique needs of women veterans with catastrophic disabilities is important to their long-term health and quality of life.

More than three quarters of a million women veterans are currently using VA health care, and this rate is expected to grow by 18,000 women per year. Women veterans with SCI/Ds are a small, but important subset of these users. Wounds and injuries that result in paralysis for military personnel during deployments are highly complex and difficult to evaluate and treat, requiring a shift in how we view and address challenges of caring for women in the VA health care system. Gender differences call for an advanced understanding of differing health care needs in order to be effective, particularly in cases involving catastrophic injury and illness.

Only three percent of veterans with an SCI/D using VA health care services are women, forming a small, but distinct subpopulation. It is essential this cohort not be overlooked. They tend to be younger than the general SCI/D veteran population and have a higher distribution of medical diagnoses, as well as a higher rate of mental illness than their male counterparts.[1]

Living with an SCI/D has a profound effect not only on the individual, but also their close family members, friends, and society as a whole. These women veterans are less likely

[1] Curtin, C. M., Suarez, P. A., Ponio, L. A. D., & Frayne, S. M. (2012). Who are the women and men in Veterans Health Administrations current spinal cord injury population? The Journal of Rehabilitation Research and Development, 49(3), 351. doi: 10.1682/jrrd.2010.11.0220Who are the women and men in Veterans Health Administration's current spinal cord injury population? (va.gov), pg. 357.

to be married. This trend is similar to that of the general women veteran population where there are many factors that cause lower marital rates. However, it is of greater concern for women with SCI/D because marital status is linked to life satisfaction following a catastrophic disability. Many spouses and immediate family members serve as caregivers to veterans with SCI/D, but women veterans are more likely to have a paid attendant as a caregiver.

Also, the longer a person with an SCI/D stays at home and in bed, the more likely the individual is to have reduced life satisfaction. Women with SCI/D tend to remain in bed and at home at significantly higher rates than men. They are also more reliant on public and paid transportation and may find it more challenging to get to and from work, meet family obligations, and attend medical appointments. So, it is essential VA ensures these women have the benefits and health care they need to live as independently and actively as possible.

Congress must conduct oversight to ensure the needs of women veterans with catastrophic disabilities, including SCI/D, are being met by VA and that any programming and facilities are accessible to people with disabilities. As Congress develops strategies and policies for VA to follow, additional emphasis is needed to ensure women veterans with SCI/D are incorporated into these plans.

Accessibility of VA Facilities

As the number of women veterans using VA health care continues to rise, it is paramount that those living with SCI/D have access to comprehensive gender-specific mental and physical health care with high standards of care regarding the quality, privacy, safety, and dignity of that care. VA has developed a robust SCI/D system to serve the general needs of veterans with SCI/D, but greater emphasis is needed on caring for women with SCI/D.

PVA women veterans report they are generally satisfied with the care they receive within VA's SCI/D System of Care. However, there is a persistent lack of coordination of care when a woman veteran must utilize care outside of the SCI/D system in the local community or other sections of the VA health care system. We have heard reports from some of our women members that they are sent to community clinics that did not have physically accessible imaging machinery or examination tables. When VA sends a veteran with SCI/D to a community care provider for breast imaging, it is important to ensure the health care provider has accessible equipment, appropriate staffing, and knowledge in the care of veterans with SCI/D to maintain the health and well-being of these women.

Attention must also be given to infrastructure barriers. While the majority of care provided for veterans with SCI/D is within the VA's SCI/D System of Care, veterans must also access other VA facilities for other specialty, mental health, OB/GYN, and ER care. The facilities in these buildings are not always accessible for non-ambulatory users.

PVA has an architecture program specifically for this purpose and stands ready to lend support to VA in the development and remodeling of VA facilities to ensure access for all

women veterans. We are pleased that we have recently seen an increase in the number of VA women veteran clinics requesting our assistance.

Along with accessibility, VA should establish a plan for projecting future demand and capacity requirements that would enable the Department to meet the anticipated needs of women veterans in VA facilities. As the number of women veterans who utilize VA's system of care increases, there is a pressing need to guarantee the availability and quality of the care provided.

Three massive pieces of veteran centric legislation were passed last year: Public Law No: 116-315, Johnny Isakson and David P. Roe, M.D. Veterans Health Care and Benefits Improvement Act of 2020, which included many provisions of the Deborah Sampson Act; Public Law No: 116-214, the Veterans' Comprehensive Prevention, Access to Care, and Treatment Act of 2020, or Veterans' COMPACT Act; and Public Law No: 116-171, the Commander John Scott Hannon Mental Health Care Improvement Act. As the VA works to implement the provisions in these bills, Congress must ensure robust oversight of the women veteran specific sections is conducted with this population in mind.

Also, as the country increases efforts to get individuals vaccinated, many veterans who have been postponing important annual care will be returning to VA in high numbers. Putting off breast examinations, pap smears, and prostate exams gives unidentified cancers—of which veterans have higher incidence rates—the chance to fester and delays time-sensitive treatments. It is essential Congress provides VA the resources it needs to deal with the surge of veterans seeking to resume these procedures once the pandemic has subsided.

Long-Term Care Access

The nation's lack of adequate long-term care (LTC) options presents an enormous problem for people with catastrophic disabilities who, as a result of medical advancements, are now living longer. There are few LTC facilities that are capable of appropriately serving veterans with SCI/D. VA operates six such facilities—only one of which lies west of the Mississippi River. Many aging veterans with SCI/D need VA LTC services but the Department only has the capacity to provide this kind of care for less than 200 patients. As a result, the need far exceeds VA's specialized LTC bed capacity.

When the demand for VA LTC beds exceeds capacity, VA has the authority to place the veteran in a community nursing home facility. However, in some areas, it is nearly impossible to even find community placements for veterans who are ventilator dependent and those with bowel and bladder care needs. Furthermore, providers in community nursing homes are not trained in providing SCI/D care. This often results in compromised quality of care and poor outcomes.

VA must expand the number of VA specialized LTC facilities and LTC SCI/D beds across the VA health care system. As VA plans and Congress funds the future of VA LTC, it is essential the needs of women veterans are incorporated in those plans. Women live longer than men and live with higher rates of disability and chronic health problems. Women veterans with SCI/D tend to rely on hired home care verses a family member for

caregiving needs. Nearly half of American women over the age of 75 live alone versus only a quarter of men.

As the ever-growing population of women veterans using the VA ages, it is essential we act now. Plans should ensure facilities can meet the needs of women veterans. In about half of VA LTC facilities, the rooms are shared or share a bathroom. Because the population of women needing this care is small, this can mean a bed or room is left unused to ensure the safety, privacy, and protection of a women veteran. VA should be conducting research now to see what the unique needs of women veterans are and incorporate their findings in long-range plans for LTC.

Research

Research is the key to improved health outcomes. The startling lack of research on women with an SCI/D, regardless of veteran status, is a great concern for PVA. While there is significant research on SCI/D, few studies focus on how it impacts women. Much of what is available on women with SCI/D focuses on reproduction or depression. To demonstrate this point, in 2017, the Minneapolis VA Evidence-Based Synthesis Program published the results of a systematic search of research related to female veterans' health published from 2008 through 2015. Of those selected for the publication, only one related to women veterans with SCI/D.[2]

Many of the mental health issues women veterans face, such as suicide, depression, and substance use disorder, are also present among women veterans with SCI/D. But women with SCI/D have increased rates of anxiety which due to the nature of their injuries, may not manifest itself in a way that is readily identifiable. To better serve the mental health needs of women veterans with SCI/D, we need research that incorporates gender differences to give us a better understanding of the differing mental health care needs for individuals with catastrophic injuries or illnesses. Congress must mandate and fund VA to conduct research on the unique health care and economic opportunity needs of this population.

At the end of March 2020, PVA along with the Consortium for Spinal Cord Medicine published a Mental Health Clinical Practice Guideline called, "Management of Mental Health Disorders, Substance Use Disorders, and Suicide in Adults with Spinal Cord Injury." The guidelines give recommendations to health care providers to improve mental health screening, assessment, and treatment of individuals with SCI/D. We believe it will be helpful for clinicians and policymakers.

VA must also ensure that prosthetists and administrators at every level understand women's prosthetic needs. To advance the understanding and application of prostheses for women, VA must include academic affiliates, other federal agencies, and for-profit industry in their research. The needs of catastrophically disabled women veterans must no longer be an afterthought. Instead, their needs must be a part of all decision-making

[2] Danan, E. R., Krebs, E. E., Ensrud, K., Koeller, E., MacDonald, R., Velasquez, T., Greer, N., & Wilt, T. J. (2017). An Evidence Map of the Women Veterans' Health Research Literature (2008-2015). *Journal of general internal medicine*, *32*(12), 1359–1376. https://doi.org/10.1007/s11606-017-4152-5

processes. Providers both in VA and those who serve these women in the community need to be fully educated on their specific needs and risks.

More research on the reproductive continuum of men and women veterans with SCI/D is also needed. In the past, attitudes that individuals with SCI should be "happy to be alive" and need to "learn to live without sexual pleasure" have clouded research and, if and when research was done, focused solely on matters of fertility and reproduction.[3] Until we have this research, we cannot understand all the various factors that come into play in reproductive health such as race, ethnicity, gender, and disparities in care. Likewise, there has been little research and attention given to female infertility and the impact of service on reproductive health from other military-related sources like toxic exposures from chemicals, occupational exposures, and burn pits.

Mental Health

Women veterans with SCI/D have higher rates of lifetime depression diagnosis and endorsed more depressive symptoms than their male counterparts. This lower satisfaction with life was a significant predictor of depression. A report on gender differences in depression among veterans with SCI recommended that VA health care providers conducting follow-up on depression screenings among veterans with SCI also include quality of life assessments and assessments of somatic symptoms.[4] It is also essential that providers pay attention to what social support is available to these women.[5]

Individuals with SCIs are at an increased risk of developing mental health disorders and secondary chronic diseases.[6] Almost 40 percent of individuals experience depression in the year following their injury. This can lengthen time for recovery and rehabilitation as well as increase symptoms of anxiety, catastrophic thinking, and perceived lack of control.[7]

Depression is closely associated with poor health outcomes and exposure to higher pain levels often triggers depression among members of the SCI/D community. Substance use disorders (SUDs) are prevalent and associated with poor outcomes in individuals with

[3] Anderson, K., Borisoff, J., Johnson, R. et al. The impact of spinal cord injury on sexual function: concerns of the general population. Spinal Cord 45, 328–337 (2007). https://doi.org/10.1038/sj.sc.3101977

[4] Wilson CS, Nassar SL, Ottomanelli L, Barnett SD, Njoh E. Gender differences in depression among veterans with spinal cord injury. Rehabil Psychol. 2018;63:221–9.

[5] Shackelford, M., Farley, T. & Vines, C. A comparison of women and men with spinal cord injury. *Spinal Cord* 36**,** 337–339 (1998). https://doi.org/10.1038/sj.sc.3100510.

[6] Michigan Medicine - University of Michigan. (2020, April 22). Spinal cord injury increases risk for mental health disorders. ScienceDaily. Retrieved June 25, 2020 from www.sciencedaily.com/releases/2020/04/200422101536.htm

[7] Mehta S, Orenczuk S, Blackport D, Teasell RW (2020). Mental Health after a Spinal Cord Injury. In Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Noonan VK, Loh E, McIntyre A, Queree M, editors. Spinal Cord Injury Rehabilitation Evidence. Version 7.0: p 1-54

SCI/D. Paraplegia versus tetraplegia, chronic pain, and low income are additional risk factors for SUDs among individuals with SCI. [8]

Suicide is a significant issue among our nation's veterans. In U.S. studies, individuals with SCI/D were reported to be three to five times more likely to die of suicide than were those in the general population; however, data for those injured in the last two decades are limited. Suicidal ideation is common after an SCI/D. Recent data from the VA Office of Mental Health and Suicide Prevention show a startlingly higher rate of suicide among veterans with SCI/D. Almost three times the crude rate of suicide of 17 a day among veterans.

As Congress conducts oversight on SUD treatments provided by VA, it will be important to consider whether women with SCI/D are incorporated into their planning. Recent communications with VA officials found that in fiscal year 2018, 23 VA facilities had inpatient mental health services capable of providing proper care to veterans with SCI/D. In cases where VA mental health inpatient care is not available, it is provided in alternative VA settings with adequate safety precautions (e.g. one-to-one level of observation) and strong mental health consultation services, or in non-VA settings by referral.

PVA believes it is in the best interest of our members that VA develop national protocols for providing mental health inpatient care for veterans with SCI/D and that information on VA inpatient mental health care for these veterans be tracked and reported. Residential treatment plans should be designed and built to accommodate women veterans, including those with SCI/D. It is also essential VA accounts for the needs of veterans with complex health care needs such as ventilators, bowel and bladder care, and other needs that require a higher level of attention. We have heard startling reports of veterans left in their homes to detox from SUDs because clinical facilities are not able to meet their health care needs during what can be a dangerous time.

Harassment

When veterans go to a VA facility, it is to get well, or maintain their wellness. Harassment not only takes its toll on the mental well-being of a person but also leads to physiological reactions.[9] Harassment has been a reason given for why some women veterans no longer seek care at VA, or that it causes them to have mental and physiological distress when going to VA to receive care. Most PVA members depend on VA for 100 percent of their care and are among the most vulnerable when access and quality of care is threatened.

A recent report by the VA Women's Health Research Network found that one in four women veterans reported inappropriate/unwanted comments or behavior by male

[8] Bombardier, C. H., Azuero, C. B., Fann, J. R., Kautz, D. D., Richards, D. S., & Sabharwal, S. (In Publication). Management of Mental Health Disorders, Substance Use Disorders, and Suicide in Adults with Spinal Cord Injury. Washington, DC: Paralyzed Veterans of America.

[9] Center for Victim Advocacy and Violence Prevention, University of South Florida. (2010). SEXUAL HARASSMENT [Brochure]. Tampa, Florida: Author. https://www.usf.edu/student-affairs/victim-advocacy/types-of-crimes/sexualharassment.pdf; Gale, S., Mordukhovich, I., Newlan, S., & Mcneely, E. (2019). The Impact of Workplace Harassment on Health in a Working Cohort. Frontiers in Psychology, 10. doi:10.3389/fpsyg.2019.01181.

veterans at VA facilities.[10] The report also demonstrated that these experiences negatively affect their health as those who experience harassment report not feeling welcome or safe and delaying or missing appointments. Veterans who identify as LGBTQ also face harassment at VA facilities. It is essential VA work expeditiously and fervently to eliminate this harmful behavior immediately.

VA facility leaders must be held accountable for providing access to comprehensive gender specific mental and physical health care, as well as ensuring high standards of quality, privacy, safety, and dignity. Research shows that VA is the best place for a veteran to receive comprehensive care. Therefore, harassment has no place within the walls of a VA facility. PVA hopes that measures to end harassment at VA included in the Johnny Isakson and David P. Roe, M.D. Veterans Health Care and Benefits Improvement Act of 2020 are implemented swiftly and Congress conducts oversight to see what else is needed to eliminate this barrier to care.

Also, people with disabilities are more likely to be sexually assaulted than their non-disabled counterparts.[11] Often, disability status is never collected, reported in assault cases, or even inquired about for rape survivors. If sexual assault advocates are not properly trained they may unwittingly contribute to people with disabilities remaining an under-served population.[12]

One step VA can take to better serve all veterans under its care is to devote attention to a program that will eliminate the current environment of harassment at VA facilities. Harassment comes in all forms and is a barrier to care that is only now really being brought to light. VA must continue its Stand Up to Stop Harassment campaign in VA medical centers and request adequate funding to promote and educate VA stakeholders to achieve the necessary cultural changes needed to remove barriers to heath care within VA for all veterans.

This is also a good time for VA to review existing policies and procedures for reporting of sexual assaults within VA to ensure we are meeting the needand capturing the full situation within its facilities. We hope part of the review process would include greater scrutiny of what, if any, protections are in place to promote the safety of catastrophically disabled veterans and ensure they are not re-victimized or assaulted for the first time while under VA care. At the same time, VA should also ensure that veterans service organizations (VSOs) have an active role in this process.

IVF

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[10] Klap, R., Darling, J. E., Hamilton, A. B., Rose, D. E., Dyer, K., Canelo, I., Haskell, S., & Yano, E. M. (2019). Prevalence of Stranger Harassment of Women Veterans at Veterans Affairs Medical Centers and Impacts on Delayed and Missed Care. *Women's health issues: official publication of the Jacobs Institute of Women's Health*, *29*(2), 107–115. https://doi.org/10.1016/j.whi.2018.12.002

[11] Strauser, D. R., Lustig, D. C., & Uruk, A. C. (2007). Differences in Self-Reported Trauma Symptomatology Between Individuals With and Without Disability: An Exploratory Analysis. Rehabilitation Counseling Bulletin, 50(4), 216–225. https://doi.org/10.1177/00343552070500040301.

[12] Gorden, Melody L. (2013). Disabled Sexual Assault Victims: Perceptions of Sexual Assault Professionals on Barriers to Providing Services to Disabled Sexual Assault Victims. Retrieved from Sophia, the St. Catherine University repository website: https://sophia.stkate.edu/msw_papers/182.

In September 2016, Congress temporarily authorized VA to provide IVF services to veterans with severe service-connected conditions that prevent the conception of a child. IVF services became available at VA in January 2017, and approximately 500 veterans and their spouses have used this service to begin or grow their families since that time. In 2018 that authorization was extended and continues so long as it is funded each year.

Although VA covers certain therapies for those with service-connected disabilities that result in infertility, there are gaps in this care. PVA supports making IVF services a permanent part of the health benefits package for veterans enrolled in VA health care. We would also like to see the services expanded. VA's current temporary authority prohibits the use of gametes that are not a veteran's and his or her spouse's. Because they require donated gametes, they are ineligible for IVF through VA. This is an unexplainable requirement that only harms those who need this service the most. A cruel irony of the prohibition of donated gametes for IVF is that there is no such prohibition when veterans pursue artificial insemination. Only in the provision of IVF can VA not authorize care if the use of donated gametes is necessary. Congress should repeal this restriction and allow other services to address the needs of women veterans whose injuries prevent a full-term pregnancy.

Also, due to the complex care needs of women veterans with SCI/D, many of them are unable to carry a pregnancy to term. These women need the services of a surrogate in order to have a child. We call on Congress to mandate that VA establish permanent authorization of assistive reproductive therapies to include IVF services, gamete donation, and surrogacy for veterans with service-connected infertility, and include the treatment of the veteran spouses in applicable cases.

There is always room for improvement in meeting the gender-specific reproductive health care needs of catastrophically disabled women. PVA encourages VA to ensure SCI/D and other specialty care providers collaborate with the mainstream VA health system so veterans with SCI/D will receive comprehensive health care. This will help ensure all VA health care providers are aware of the specific heath concerns of veterans with SCI/D when it comes to contraception and family planning. Women veterans should be asked early and often about their plans to have a family, sexual health, and screening for caregiver or inter domestic partner violence (IPV). VA providers are just now getting regular training on IPV screening. Many are uncertain how to respond if a veteran says yes. Providers should also be screening for rape as it has been found to be the trauma most associated with Posttraumatic Stress Disorder (PTSD) among women.

Benefits

The benefits provided by the Veterans Benefits Administration (VBA) impact the overall quality of life for women veterans and often act as the first stop for veterans accessing health care. Sadly, several administrative changes last year eroded the ability of VSOs to receive timely notifications and review cases under their purview. PVA supports all efforts to restore and improve the tools service officers need to serve veterans seeking benefits.

Additionally, we have two specific concerns with last year's announcement by VBA that most of the compensation and pension (C&P) exams are being sent to contractors. First, if one of our members with MS had a C&P exam at a VA medical center, it would be with

a neurologist. If that same member had a contract exam, the member may see a Primary Care doctor, Family Practitioner, an Internal Medicine specialist, or other physician who may have little to no experience with MS and neurology. From our experience, this quickly leads to inadequate exams and poor decisions that must be appealed. Our second concern is the contractors' inexperience with VA and a lack of knowledge about veterans. VA must often go back to contractors multiple times for clarifications. This can cause lengthy delays in decisions on a claim and result in poor decisions that must be appealed. The responsibility to conduct evaluations for complex medical injuries and diseases like SCI/D and ancillary conditions should be retained by VBA.

In addition to living with SCI/D, PVA members may also be military sexual trauma (MST) survivors. One complaint we receive from our members is that even when they request a gender specific person to handle their MST-related claim, often that request is not honored. VA should make every effort to ensure these requests are accommodated.

We appreciate the opportunity to submit our views on some of the issues we are looking at in the 117th Congress and with the Task Force on Women Veterans. Because care for women veterans with SCI/D is complex and requires thorough knowledge of the complete picture of care being provided, there are always actions VA can take to improve the experience of these veterans. We look forward to working with the Subcommittee and the Task Force on ways to further improve care and benefits for women veterans.

Information Required by Rule XI 2(g) of the House of Representatives

Pursuant to Rule XI 2(g) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2021

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $455,700.

Fiscal Year 2020

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $253,337.

Fiscal Year 2019

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $193,247.

Disclosure of Foreign Payments

Paralyzed Veterans of America is largely supported by donations from the general public. However, in some very rare cases we receive direct donations from foreign nationals. In addition, we receive funding from corporations and foundations which in some cases are U.S. subsidiaries of non-U.S. companies.