

## WOUNDED WARRIOR PROJECT Statement for the Record

## "Everyday Heroes: Supporting the Veteran Caregiver Community"

## COMMITTEE ON VETERANS' AFFAIRS U.S. HOUSE OF REPRESENTATIVES

### September 25, 2024

Chairman Bost, Ranking Member Takano, and Members of the Committee – thank you for inviting Wounded Warrior Project (WWP) to share its perspective on the challenges facing the veteran caregiver community. Caregivers are a crucial and indispensable part of the community that supports the warriors WWP was founded to serve. We appreciate your effort to convene this critical oversight hearing and are pleased to help inform and guide future action to enhance veteran caregivers' well-being.

Wounded Warrior Project was founded to connect, serve, and empower our nation's wounded, ill, and injured veterans, Service members, and their families and caregivers. We are fulfilling this mission by providing more than 20 life-changing programs and services to over 218,000 registered post-9/11 warriors and 54,000 of their registered family members. These direct services span mental, physical, and financial domains to create a 360-degree model of care and support, including intensive programming focused on connection, independence, and wellness for severely injured veterans and the caregivers who play diverse and meaningful roles in their lives.

Wounded Warrior Project also provides support to caregivers and warriors by partnering with organizations that not only conduct research but provide specific services or programming directly to caregivers. These partnerships allow us to make an even greater impact and deliver better quality of life and care. Since 2012, WWP has supported 25 organizations that provide direct programs to caregivers – including clinical mental health services, respite, support for children in caregiving families, and other resources. The research, programs, and partners help inform our perspectives on what more can be done to support this vital group. Additionally, WWP has teamed up with the Elizbeth Dole Foundation to action critical findings from groundbreaking studies through the creation of the Hidden Helpers Coalition – a collaborative network of more than 100 public and private sector partners committed to supporting children and young adults in caregiving homes.

### Advocacy Before Congress

Caregivers make sacrifices every day to ensure that our nation's most severely wounded, ill, and injured Service members and veterans are taken care of. At WWP, we recognize these sacrifices and are dedicated to providing support for both the warriors and their caregivers programmatically and through our advocacy before Congress. Multiple pieces of legislation introduced in during the 118<sup>th</sup> Congress would address challenges faced by caregivers. Key legislation includes: the *Elizabeth Dole Home Care Act* (H.R. 542), introduced by Rep. Julia Brownley (D-CA-26); the *Caregiver Outreach and Program Enhancement (COPE) Act* (H.R. 3581), introduced by Rep. Jen Kiggans (R-VA-02); and the *Veterans Caregiver Application and Appeals Reform (CARE) Act of 2023* (H.R. 4518), introduced by Rep. Donald Davis (D-NC-01). Similar efforts can be found in the U.S. Senate.

Recognizing that these bills were complementary, key sections were included within the *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (H.R. 8371), a veterans omnibus legislative package offering comprehensive solutions, introduced by Rep. Juan Ciscomani (R-AZ-06). WWP strongly supports each of these bills individually but believes the Elizabeth Dole package provides the best and most comprehensive legislative solutions to more fully address the needs of our nation's caregivers. The remainder of this statement outlines WWP's previous efforts to support caregivers through congressional action and provides a present-day perspective on how the Committee may choose to pursue oversight and policies to support our nation's hidden heroes.

# **Direct Support for Caregivers: The Program of Comprehensive Assistance for Family Caregivers (PCAFC) (2010)**

#### Key Facts for 2024<sup>1</sup>

- **Program participation**: Of the nearly 16% of WWP warriors who report receiving aid and assistance from another person due to service-connected injuries or health problems, approximately 30% are participating in PCAFC.
- Volume of caregiving provided: WWP warriors enrolled in PCAFC rely on caregivers who regardless of employment status and type (at home, virtual, hybrid, part-time, full-time, or unemployed) generally spend more than 50 hours per week providing caregiving assistance. Nearly half of warriors who require aid and assistance (48.2%) reported needing 40 hours or more per week.

Historically, WWP advocacy on behalf of severely injured warriors and their caregivers helped secure passage of the *Caregivers and Veterans Omnibus Health Services Act of 2010* (P.L. 111-163). This legislation launched the PCAFC, which was originally designed for severely wounded, ill, and injured post-9/11 veterans and caregivers and has provided this community with critical support towards sustaining meaningful lives at home and in the care of loved ones serving as caregivers. WWP was pleased to support the *VA MISSION Act* (P.L. 115-182), which expanded PCAFC to veterans and caregivers of all generations, but which also

<sup>&</sup>lt;sup>1</sup> The figures below are from WWP's 2022 Annual Warrior Survey, which can be viewed at

https://www.woundedwarriorproject.org/media/ylwhpx4h/wwp-2022-annual-warrior-survey-full-report.pdf.

allowed the U.S. Department of Veterans Affairs (VA) to modify eligibility criteria in ways that have put this critical program out of reach for many deserving veteran caregiver households.

Following passage of the VA MISSION Act, PCAFC eligibility criteria was modified from a system that paid stipends to family caregivers based on the number of hours spent providing personal care services to veterans to a system that requires the caregiver to provide personal care services every time a veteran completes one of several activities of daily living (ADLs). As expressed previously to the Committee, we are concerned that the new system excludes too many veterans with moderate and severe needs that the program was originally designed to cover. Among veterans and caregivers in the WWP community with a service-connected disability rating of 70 percent or more (a criteria for the new PCAFC eligibility), less than two percent of veterans are completely dependent on someone else to complete the ADLs that are considered as part of PCAFC eligibility. Oftentimes, veterans with certain conditions, such as amyotrophic lateral sclerosis (ALS) or multiple sclerosis (MS), experience fluctuations in symptoms. The variability and unpredictability of their conditions means they may not need help with ADLs every time, but during symptom flares, need a caregiver's support.

We urge Congress to keep these considerations in mind as they continue to monitor the program to ensure that veterans and caregivers in need of heightened support are receiving the care they need. The financial impact of PCAFC participation can make a critical difference for post-9/11 households and provides a compelling reason to ensure this program is working for them. According to new RAND research conducted in 2023, 70% of caregivers to military/veteran recipients aged 60 and under report difficulty paying bills compared to only 48% of those caring for someone over 60.

In addition to maintaining vigorous oversight of VA's implementation of the PCAFC and any forthcoming regulatory adjustments to eligibility standards, the Committee can pursue legislative initiatives to better support caregivers seeking assistance through PCAFC.

• **Transitions away from PCAFC**: The *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (Sec. 124) (see also *Elizabeth Dole Home Care Act* (Sec. 5)) would help ease the transition of caregivers who are ineligible or are discharged from PCAFC by offering them the option to enroll in VA's Program of General Caregiver Support Services (PGCSS). It would also allow the veteran or caregiver to be assessed for participation in any other available VA program for home- and community-based services and would require VA to assign a Caregiver Support Coordinator to provide a smooth and personalized transition to each veteran or family caregiver discharged from PCAFC to help them navigate the process.

We further recommend that such coordination be extended to those who are and continue to be successfully enrolled with PCAFC. Services provided by Geriatrics and Extended Care (GEC) programs will not necessarily overlap with the "personal care services" provided by the family caregiver, and transparency on eligibility and instructions for applying for these other programs is often lacking under current VA coordination practices. In either case, improvements designed to help connect these veterans and caregivers to other programs that may provide needed assistance can be a critical backstop. Individualized engagement – or at

least clearer presentation of options and avenues to support – has potential to greatly improve how efficiently and effectively veterans are connected to the programs and resources that have been put in place for them to use.

**Service organization advocacy**: WWP supports efforts to allow for clearer paths for veterans and caregivers to engage with service organizations that can help guide their paths to care and support. The *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (Sec. 129) (see also *CARE Act* (Sec. 3)) would allow Veterans Service Organizations and other accredited agencies to advocate for veterans applying for entry into the program, a process that can be complicated for veterans and caregivers to navigate.

# Care Coordination for Severely Wounded Service Members and Veterans: The Federal Recovery Coordination Program (FRCP) (2014)

### Key Facts for 2024

- Long-term care for younger veterans: Younger veterans are using VA's GEC programs in growing numbers. According to VA's FY 25 budget proposal, 29% of GEC program users in 2023 were veterans under the age of 65 (~146,000 veterans). In 2018, veterans under the age of 65 were 25% of GEC program users (~112,000 veterans).
- **Demand for long-term care**: The number of veterans age 65+ who are significantly disabled is expected to rise by over 50% in the next ten years and Home-based primary care usage is expected to rise by nearly 50%.<sup>2</sup>

Within the community of post-9/11 wounded, ill, and injured veterans that WWP serves, caregivers play an indispensable role in maintaining a high awareness of the physical, mental, behavioral, and financial health needs of those they care for. Navigating myriad federal, state, and community-based resources to assist their care journey is part of the caregiving role for many. As veterans with chronic health issues continue to age and address evolving challenges, their need for treatment, therapies, and caregiving support will only increase.

Caregivers' needs must be carefully followed as well, particularly as they age and become less able to care for veterans. Congress and federal agencies can be at the forefront of planning for this future by putting systems in place now to help veterans and caregivers navigate the resources available to them. Models from the past can offer a vision for how to better serve this community and create better outcomes in the near and long term.

To assist veterans and caregivers in navigating the complex environment of care available to them, the Federal Recovery Coordination Program (FRCP) was created as a joint effort between VA and the U.S. Department of Defense (DoD). The intent behind the FRCP traces back to the President's Commission on Care for America's Returning Wounded Warriors<sup>3</sup> recommendation for the federal government to immediately create and coordinate comprehensive recovery plans for seriously injured Service members.<sup>4</sup> Today, Federal Recovery

 <sup>&</sup>lt;sup>2</sup> Figures are drawn from the VA Veteran Experience Office's "Choose Home Initiative Final Report; January 2020" unless noted otherwise.
<sup>3</sup> The group is often called the "Dole-Shalala Commission" in reference to its co-chairs.

<sup>&</sup>lt;sup>4</sup> See PRESIDENT'S COMMISSION ON CARE FOR AMERICA'S RETURNING WOUNDED WARRIORS, SERVE, SUPPORT, SIMPLIFY, 5, 13-14, (July 2017), available at https://www.patriotoutreach.org/docs/presidents-commission-report-july-2007.pdf.

Consultants (FRCs) are located at nine sites across the country or are available to provide virtual consultations across the nation.<sup>5</sup> FRCs are unique in their ability to operate within both DoD and VA, working with wounded warriors throughout their recovery and eventual reintegration into the community.

FRCs were originally designed to liaise between a veteran's Care Management Team, composed of clinical providers, DoD Recovery Care Coordinators, service wounded warrior programs, Medical Case Managers, Non-Medical Case Managers, and any others involved in a patient's care. An FRC does not provide direct services but identifies gaps in patient needs that the Care Management Team is unable to fill and facilitates access to resources provided by State and Federal governments, non-profit organizations, medical centers, and the veteran's local community. Their holistic approach is intended to synchronize four rehabilitation factors: benefits; education, training, and employment; medical and rehabilitative care; and family support services. FRCs are available to those wounded warriors who are in a military acute care setting and require high-intensity care management.

While FRCs have been a successful tool in the past, investment in the FRCP has waned as demand has declined, leaving significant gaps in case management services for veterans with complex cases. Individual Case Managers are siloed within their respective agency jurisdictions without an FRC to manage care enterprise-wide and longitudinally. As a result, patients may miss out on valuable resources due to insulated treatment planning by the Care Management Team, further obscured by the vast number of programs, services, partnerships, and benefits advertised to patients and caregivers – and which are often challenging to navigate for trained social workers not part of the FRCP. In this context, the community would likely benefit from a congressionally mandated report on the evolution of the FRCP<sup>6</sup> to better align resources moving forward.

On a similar scale, WWP supports the creation of a system to help centralize care coordination and patient advocacy, especially for those veterans with the most complex needs who often depend on caregivers. This approach should include a mechanism to help identify those most in need of assistance with care coordination, through screening during enrollment, identification by providers and social workers of current enrollees, and a process for veterans and caregivers to self-identify as in need of these services. Additional elements should include a central hub for coordinating care across different healthcare settings to ensure that all providers involved in the veteran's care have access to the necessary information and can collaborate effectively, as well as the ability for health advocates (like WWP) to intervene and assist with necessary appeals.

We also recommend the designation of a VA social worker at each VA Medical Center with enhanced authority to serve as the subject matter expert for the facility. This social worker would provide mentorship, oversight, and assistance to other social workers executing care

<sup>&</sup>lt;sup>5</sup> OFF. VA/DOD HEALTH AFFAIRS, U.S. DEP'T OF VET. AFFAIRS, FACT SHEET: FEDERAL RECOVERY CONSULTANT OFFICE (Jan. 2024), available at https://www.va.gov/VADODHEALTH/docs/FRC\_Office\_Fact\_Sheet20240131.pdf.

<sup>&</sup>lt;sup>6</sup> In February 2018, the Executive in Charge, Veterans Health Administration, approved the modernization of the program formerly known as the Federal Recovery Coordination Program or FRCP in response to the Presidential Executive Order (EO), "Comprehensive Plan for Reorganizing the Executive Branch" which directed the federal government to improve the efficiency and effectiveness by eliminating redundancies and to reorganize governmental functions. From that point forward, FRCP has referred to the Federal Recovery Consultant Office (FRCO).

coordination at the service level and would have the authority to expedite needed care across all service areas while facilitating communication between different providers, and helping veterans navigate the healthcare system. Given how often veterans receive care outside of VA facilities, it is also necessary to ensure that medical information is appropriately communicated, and that care coordination exists between all primary, specialty, and residential care providers. Care plans, treatments, and the availability for continuing pharmaceutical support of treatments must be communicated effectively to those provider teams involved in an individual's care, whether inside or outside of VA.

Action that Congress can take now is found below:

• Outreach, education, and transparency: WWP supports providing enhanced tools and resources for veterans and caregivers. The *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (Sec. 132) (see also *Elizabeth Dole Home Care Act* (Sec. 6)) would require VA to develop a website for information and resources relating to the GEC home and community-based services. This provision would require VA to create and maintain a periodically updated, centralized website as a clearinghouse for information on caregiver programs, which contains an informational assessment tool that explains eligibility, and lists required procedures for directors of medical centers to follow in determining eligibility and suitability for program participation.

WWP believes that a menu of available program options tailored to the veteran/family and based on his or her needs and eligibility would maximize the use and impact of those services. Given that many of these programs include both administrative and clinical eligibility determinations, the addition of a website that more clearly explains what programs exist, how participation in one may affect eligibility for another, and other pertinent information in a single place would be a meaningful improvement over current practice.

• Home and Community Based Services (HCBS): According to VA's FY 25 budget proposal, 29% of GEC program users were veterans under the age of 65. That figure represents a 13% increase over 2019, when veterans under age 65 accounted for 16.7% of GEC program users. While the decision to choose home may not be appropriate or desirable in all cases, VA also notes that the increased use of home and community-based care to allow veterans to better age in place is also advantageous to the veteran and VA by attempting to prevent or delay the need for more expensive nursing home care and to meet the veteran's preference in a veteran-centered approach. Availability of these programs will be critical for post-9/11 veterans and caregivers both now and as they age.

Under current law, all veterans enrolled in VA's health care system are potentially eligible for Long Term Services and Support (LTSS), a suite of Veterans Health Administration (VHA) programs that includes facility-based services, end-of-life services, and – most critically to the post-9/11 generation's severely wounded warriors – geriatric outpatient programs and home and community-based services. Yet in practice, many younger veterans who would prefer to stay at home and would benefit from these services are challenged by issues related to awareness, access, and coordination of care within VA. The *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* would place VA on a track to address many of the problems experienced by post-9/11 wounded warriors (and their caregivers) who currently use, or may benefit from, GEC programs. Section 120 would increase the expenditure cap for noninstitutional care alternative programs to nursing home care from 65 percent to 100 percent. Making needed care more affordable by lowering out-of-pocket costs is critical to the population WWP serves. According to our 2021 Annual Warrior Survey, the odds of reporting financial strain for WWP warriors requiring aid or assistance is 2.1 times as likely as that among WWP warriors who don't require aid or assistance.

Section 123 would expand the availability of VA's existing home and community-based services, including Veteran Directed Care (VDC) and the Home Maker and Home Health Aide Program, to all VA medical centers. It would also codify VA's existing Home-Based Primary Care Program and Purchased Skilled Home Care Program to better furnish in-home health care for veterans.

Section 130 would require VA to conduct a review of each program administered by the Office of Geriatric and Extended Care and the Caregiver Support Program to eliminate service gaps at medical centers and provide for the clinical needs of veterans. It would also help ensure consistency in program management; ensure proper coordination between HCBS programs; and ensure availability of and access to HCBS for veterans, including for rural veterans. This is particularly important as younger veterans with long term care needs and their caregivers are often overlooked for programs like Veteran Directed Care and Home-Based Primary Care because they are a small – but vulnerable – portion of the eligible population. In many cases, they are in desperate need of these services but simply are not aware they exist. Because this population is relatively small and geographically diverse, increased training to identify younger veterans in need of long-term support services may be needed.

# Supportive Living Options for Veterans with TBI: The Assisted Living for Veterans with TBI (AL-TBI) Pilot Program (2008)

#### Key Facts for 2024<sup>7</sup>

- Aging caregivers: Post-9/11 caregivers are aging alongside the veterans they support. As life circumstances change over time, caregivers who are parents (6.1%), friends and neighbors (17.9%), and siblings/in-laws/other relatives (29.3%) may become more likely to seek other care arrangements.
- **Financial hardship**: 36% of post-9/11 military/veteran caregiver households earn less than 130% of the federal poverty line. 60% of those homes report difficulty paying bills; 58% report no rainy-day funds, and 44% lack health insurance.

Brain health plays a crucial, yet often overlooked, role in overall quality of life for many of the warriors that WWP serves. Unfortunately, brain trauma, more specifically traumatic brain injury (TBI), is not uncommon for post-9/11 veterans. The Defense Health Agency reports that

<sup>&</sup>lt;sup>7</sup> Figures within this section are drawn from RAND's 2023 caregiver survey.

over 505,000 Service members worldwide suffered from TBIs between 2000 and early 2024.<sup>8</sup> Among warriors responding to our 2022 Annual Warrior Survey, 36.5% self-report experiencing TBI during their military service. Based on these concerns, more can and should be known about the expected course of neurological and cognitive functioning after TBI and how veterans – and their caregivers – can expect to rely on VA for long-term care and support.

The need for long-term care is further complicated by the chronic and degenerative conditions that may accompany traumatic brain injury (TBI), such as Alzheimer's disease, amyotrophic lateral sclerosis (ALS), Parkinson's disease, and early-onset dementia. While many caregivers are able to provide essential support for these veterans, their ability to do so may diminish as the veterans' conditions progress, and as the caregivers themselves age and face their own declining health and capacity to provide the same level of care.

With the rise in veterans living with brain injury, WWP has seen a related rise in veterans with a need for more intensive care and services. Long-term services and supports, such as VA's facility-based services, end-of-life services, geriatric outpatient programs, and home and community-based services, are increasingly in demand from the population that we serve, and we continue to see an increase in the usage of these programs amongst veterans under the age of 65. We believe it is essential to support policies that promote the utilization and success of VA's long-term care programs for younger veterans, including those who have suffered TBIs in service.

Investments into the study and treatment of TBI have progressively expanded since 9/11. These include both internally conducted studies and research as well as partnerships through medical facilities, such as Boston University. The Assisted Living for Veterans with TBI (AL-TBI) Program (as part of the 2008 NDAA) was established by Congress in acknowledgement of both the benefits of such treatment and the growing need to provide better options to TBI, caregivers and their families. The legislation was designed to respond to and address situations where young veterans were in VA nursing care designed for aging veterans while civilian rehabilitation facilities existed for younger groups with TBI. While the program served over 250 veterans over 8 years, it was allowed to sunset, leaving patients and families to (in most cases) find different resources to fill the void.

The AL-TBI Program was written in response to a need for specialized residential care and rehabilitation with the purpose of enhancing rehabilitation, quality of life, and community integration. Nothing suggests that this need for care has expired despite the program being allowed to terminate. The program served several veterans who were diagnosed with moderate to severe TBI and required assistance with normal daily activities.

Wounded Warrior Project supports committee oversight into the long-term living options for veterans with TBI and other chronic illnesses that will contribute to challenges living independently that caregivers have helped address for years. Additionally, Congress can take legislative action now to help guide public policy around VA's ability to provide supportive

<sup>&</sup>lt;sup>8</sup> DEF. HEALTH AGENCY, U.S. DEP'T OF DEF., DOD NUMBERS FOR TRAUMATIC BRAIN INJURY WORLDWIDE (May 2024), *available at* https://health.mil/Reference-Center/Reports/2024/08/29/2000-2024-Q1-DOD-Worldwide-Numbers-for-TBI.

living services other than State Veteran Homes, nursing homes (Community Living Centers), and medical foster homes.

• Assisted living: WWP supports the *Expanding Veterans' Options for Long-Term Care Act* (S. 495, H.R. 1815), included within the *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (Sec. 127). As indicated in RAND's 2023 caregiving survey, the caregiver dynamic is changing as veterans age. As a result, more siblings, friends, and more distant relatives are assuming the caregiver role. While VA is generally prohibited from paying for housing, this bill would require VA to implement a pilot program through September 30, 2026, that will assess the effectiveness of providing assisted living services to eligible veterans. The pilot facilities must be in geographically diverse regions, at least one of which serves veterans in rural or highly rural areas and include at least one State home. Upon termination of the pilot program, VA would provide all participants the option to continue to receive assisted living services at the site they were assigned at VA's expense. This program would allow veterans with serious needs more flexibility and the option to live more independently while potentially demonstrating cost-savings to VA, as these assisted living services can sometimes be provided in lieu of more expensive nursing home care.

## **Other Challenges to Consider**

### Addressing Caregivers' Mental Health Needs

• Among post-9/11 caregivers polled by RAND in 2023, one third meet probable criteria for depression, and approximately one in ten have had thoughts of suicide in the past year. Unfortunately, over a quarter needed mental health care in the past 12 months but did not receive it.

Caregivers play an indispensable role in helping to coordinate services, locate resources, advocate, and provide aid and assistance in the home. Given the immense sacrifices most military and veteran caregivers make to ensure their loved one is well taken care of, many of them experience a great toll on their own mental health and wellbeing. Many caregivers suffer from high rates of depression, financial hardship, and burnout. Substance use, particularly alcohol use, may also be a concern: over half of all post-9/11 military/veteran caregivers who drank alcohol met criteria for potentially hazardous use. Critically, caregivers are also on the frontlines of the veteran suicide crisis, watching for every emotional trigger, and monitoring every change in behavior.

We are pleased by proactive steps VA is already taking to increase its support of caregivers – much of which can help ameliorate mental health concerns. During its "Year of the Caregiver – the Whole Caregiver," the Caregiver Support Program (CSP) is continuing to develop the provision of mental health services offered to caregivers by expanding the availability of virtual psychotherapy services within all 18 Veteran Integrated Service Networks (VISNs) by the end of FY24. The CSP has also funded respite liaisons at each VISN to improve access to respite for veterans and their caregivers. However, more should be done to ensure that caregivers are getting the respite and mental health support they need. Congress can support this effort by taking the following actions:

- **Respite care**: The *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (Sec. 123) (see also *Elizabeth Dole Home Care Act* (Sec. 4)) would ensure at least 30 days of respite care is provided to caregivers of veterans enrolled in the Program of General Caregiver Support Services (PGCSS), allowing the caregiver time to rest, take care of their own health needs, or see friends and family. They would also commission a VA report with recommendations on how VA can expand mental health services and support for caregivers.
- **Mental health grants**: The *Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act* (Sec. 123) (see also *COPE Act*) would also provide additional resources to address the mental health needs of veteran caregivers by authorizing VA to provide grants to organizations that support caregiver mental health and well-being. The provisions prioritize grants for areas with high rates of veterans enrolled in the family caregiver program and areas with high rates of veteran suicides or referrals to the Veteran Crisis Line (VCL). Additionally, the bill would require VA to provide outreach to caregivers about the resources available to them and provide Congress with research on the program and its outcomes.

#### **Planning for Financial Future**

• According to recent RAND research from 2023, post-9/11 caregivers show an estimated \$8,583 of annual out-of-pocket costs associated with caregiving. Further, these caregivers show an estimated \$4,522 of annual household income lost due to caregiving.

Veteran caregivers face additional burdens beyond their mental and physical health. Research shows us that caregivers also pay a financial toll for taking on the duties of caregiver. While the figures that follow are inclusive of caregivers to veterans and non-veterans, they are nevertheless illustrative of the fact that the financial future for many caregivers is unclear. Approximately 68% of caregivers today are also financial caregivers, providing financial support towards the recipient's expenses.<sup>9</sup> On average, family caregivers are spending \$7,200 per year in out-of-pocket expenses for things like housing, home modifications, and medical and transportation costs.<sup>10</sup> Family caregivers also report spending 26% of their income, on average, on their caregiving activities, an amount that substantially increases for Black and Hispanic/Latino caregivers.<sup>11</sup>

Caregiving duties can also greatly impact the caregiver's ability to maintain a career, placing them in even deeper financial uncertainty. Many caregivers face challenges finding employment that allows for the flexibility that caregiving requires. Many caregivers also place their career ambitions on hold to support their loved ones and face long-term financial uncertainty, particularly into typical retirement age. Nearly one-third of caregivers report having to change their work schedules to accommodate their caregiving duties and nearly 20% say

<sup>&</sup>lt;sup>9</sup> TIAA INST. & NEWCOURTLAND CTR. AT THE UNIV. OF PENN. SCH. OF NURSING, PLAYING THE LONG GAME: HOW LONGEVITY AFFECTS FINANCIAL PLANNING AND FAMILY CAREGIVING (NOV. 2023), *available at* https://www.tiaa.org/content/dam/tiaa/institute/pdf/insightsreport/2023-10/tiaa-institute-upenn-how-longevity-affects-financial-planning-ti-november-2023.pdf. <sup>10</sup> Id

<sup>&</sup>lt;sup>11</sup> Id.

they've had to work fewer hours.<sup>12</sup> Recent RAND research showed that only about half (52%) of caregivers for post-9/11 veterans reported having a full-time job outside of caregiving.

Time constraints can negatively impact the caregiver's ability to advance in their career and place them further behind financially. RAND recently found that 60% of caregivers reported difficulty paying bills.<sup>13</sup> Caregivers that do not have outside employment also have the burden of not having contributed to Social Security, leaving them without an additional safety net or one that will be notable less than those in the traditional workforce. Assisted living options for veterans with higher needs – and which can potentially ease caregiver responsibilities and free up time to pursue gainful employment – will come at great financial cost until VA is able to assist with room and board costs. Congress should continue to look at ways these issues can be addressed to ensure that caregivers can establish better financial security.

To these ends, WWP strongly supports the *Veteran Caregiver Reeducation*, *Reemployment, and Retirement Act* (S. 3885, H.R. 9276). This bill would increase and extend certain benefits to PCAFC – including recertification assistance, employment opportunities, retirement planning, and bereavement counseling and support – to help ensure that caregivers are supported as they move to the next phase of their lives after caregiving. Currently, caregivers who receive Civilian Health and Medical Program at VA (CHAMPVA) benefits through the Program of Comprehensive Assistance for Family Caregivers (PCAFC) lose their health insurance when the veteran dies or is discharged from PCAFC. Of note, this bill would increase the time family caregivers remain enrolled in CHAMPVA from 90 to 180 days following dismissal from PCAFC. The *Veteran Caregiver Re-education, Re-employment, and Retirement Act* would also provide caregivers financial support in renewing lapsed professional certifications; incentivize internship opportunities with employers who support caregivers in their re-entry into the workforce; and study the feasibility and advisability of caregivers contributing to personal retirement accounts to secure their financial futures.

#### **CONCLUDING REMARKS**

Wounded Warrior Project thanks the House Committees on Veterans' Affairs, its distinguished members, and all who have contributed to a robust discussion regarding caregivers. WWP stands by as your partner in meeting the needs of all who served and all who support them. We are thankful for the invitation to testify and stand ready to assist when needed on issues related to the veteran caregiver community and any others that may arise.

<sup>&</sup>lt;sup>12</sup> AARP RESEARCH, CAREGIVING OUT-OF-POCKET COSTS STUDY (June 2021), available at

https://www.aarp.org/content/dam/aarp/research/surveys\_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001.pdf.