WRITTEN TESTIMONY OF HANNAH NIESKENS, VETERAN CAREGIVER AND DOLE CAREGIVER FELLOW,

BEFORE THE SENATE SPECIAL COMMITTEE ON AGING AND VETERANS' AFFAIRS

UNITED STATES SENATE

"HEROES AT HOME: IMPROVING SERVICES FOR VETERANS AND THEIR CAREGIVERS"

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Chairmen Casey and Tester, Ranking Members Braun and Moran, and Members of the Senate Special Committee on Aging and Senate Veteran Affairs Committee, I am honored to testify today. My name is Hannah Nieskens, and I have been married to my husband, Kelly, for twenty years. I have been his caregiver for eighteen and a half of those years.

In 2005, Kelly was a 23-year-old Army infantryman deployed to Forward Operating Base McHenry in Hawijah, Iraq. Hawijah, located in the Sunni Triangle, was a hotspot for insurgency activity during the Iraq War. On May 4, 2005, during a routine patrol, Kelly's Humvee was struck by a large IED. This was the fifth time a roadside bomb had hit his vehicle since his arrival in November, but this time the damage was catastrophic. The explosion left the Humvee disabled in an 11-foot-wide crater, and the squad members, including Kelly, were knocked unconscious.

Upon regaining consciousness and exiting the vehicle, they came under sniper fire. Kelly was struck by a large-caliber rifle round that traveled through his ribs, hit his armored plates, and ricocheted multiple times through his torso before lodging near his spine. He survived thanks to the extraordinary efforts of medics, doctors, and the evacuation team.

Kelly was honorably discharged and did not receive medical retirement or Servicemembers' Group Life Insurance Traumatic Injury Protection (TSGLI). I believe this was partly because he was under a stop-loss order when he was wounded, as his formal separation date had already passed, and partly because he was a National Guardsman activated to active duty Army service and was unaware of these benefits.

Upon reintegration into civilian life, Kelly's physical limitations were evident: mobility issues, painful scars, nerve damage, neurogenic bowels, migraines, seizures, and hearing loss. However, his cognitive impairments presented the greatest challenges, including executive functioning issues, memory deficits, mood dysregulation, impaired judgment, impulse control problems, chronic sleep deficit, anxiety, difficulty establishing and maintaining relationships, and inability to concentrate.

In 2011, after being referred by Kelly's VA psychiatrist, I was accepted into the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC), which has been a lifeline for us. The support and assistance from the PCAFC staff have been invaluable in managing Kelly's care and providing support and educational opportunities for me; I have nothing but good things to say about the VA Montana PCAFC staff.

However, I did have concerns about Kelly's healthcare. The Veterans Health Administration (VHA) doctors had prescribed numerous medications to manage his symptoms with limited success. In 2016, I shared my concerns with another caregiver I had met through the PCAFC, suspecting that many of Kelly's symptoms were due to TBI rather than PTSD. PTSD typically improves with treatment, but TBI symptoms often worsen over time as the brain ages. Kelly's symptoms had steadily worsened. My friend

recommended UCLA's Operation Mend program, which provides comprehensive assessments for veterans.

Kelly was accepted to the UCLA program, and in June 2016, we traveled to Los Angeles for an 8-day evaluation. Despite the neurologist's initial expectations that a brain MRI was unlikely to show anything of significance 11 years after the injury, an MRI revealed twelve lesions on Kelly's brain, some as large as a dime, confirming a significant TBI from the blast. I recall the doctor asking Kelly if he remembered any symptoms from 2005. He said he remembered having tremendous headaches for 3-4 months and that his helmet would not fit on his head for a few weeks. However, at the time, the care for his gunshot wounds took priority.

The discovery of brain lesions, the results of UCLA clinical neuropsych testing, and a UCLA spine evaluation enabled us to reopen Kelly's Veterans Benefits Administration (VBA) benefits claim to address missing and low disability ratings. Kelly's (VBA) initial TBI disability rating had been 10%. I attribute this low rating to the lack of a comprehensive neurological exam and the absence of a brain MRI. After a thorough review of 29 sets of medical records spanning 2004-2016, Kelly received additional benefits backdated to December 2016. These included a 100% permanent and total rating, a 70% TBI rating, aid and attendance benefits, a 50% rating for migraines, and service connection for neurogenic bowels. I was also appointed his VA fiduciary due to the cognitive deficits of TBI, including impaired judgment and memory, which rendered him incompetent by VA definition.

In 2021, ten years after entering the VA's Program of Comprehensive Assistance for Family Caregivers, we were notified that Kelly needed a reassessment for our eligibility for the PCAFC program. Honestly, given the magnitude of Kelly's needs and the fact we had long been established with the program, I trusted that this process would only reaffirm what was already known. How wrong I was.

The reassessment process was grueling and heartbreaking. During a nearly two-hour virtual appointment with a contracted occupational therapist, Kelly and I had to painfully recount every limitation he faces. When Kelly became emotional while discussing toileting needs due to neurogenic bowel, the examiner was unable to see his tears, and she pressed on.

I also had to try and quantify everything I do as a caregiver. This is difficult when you have spent nearly two decades as a caregiver because all of the support I provide is so integrated into our daily lives. I did my best to recount my caregiving tasks, including personal care assistance with activities of daily living (ADLs), medication management, meal preparation, transportation, behavioral and emotional support, mobility assistance, financial management, home adaptation, and advocacy and support with healthcare providers.

The resulting report was incomplete and inaccurate. Perhaps the most egregious error was a statement that read in part, "He has had a gunshot to the head." The report also missed critical diagnoses and VBA disability ratings. For example, Kelly's VBA rated disability of status post through and through gunshot wound injury, coded with VBA diagnostic code 5320 for muscle injuries due to wounds caused by gunshots or other missiles, was recorded in his VHA records as superficial scars and back muscle impairment, as there was no equivalent diagnostic code in the VHA medical record system. His VBA rating for neurogenic bowel was recorded in the VHA system as irritable colon. Perhaps most importantly, his TBI disability, including the rating of 70%, was completely missing in the VHA record as a rated service-connected disability.

I did my best to advocate to get these disability codes fixed before submission of the reassessment document for the Centralized Eligibility and Appeals Team (CEAT) review. Despite the best efforts of the VA staff, the incorrect diagnoses could not be corrected due to inequivalent diagnostic codes between the VBA and VHA systems.

The reassessment outcome was stunning. Ironically, on March 23, 2022, the very day of the Senate Veteran's Affairs committee hearing entitled "Honoring Our Commitment: Improving VA's Program of Comprehensive Assistance for Family Caregivers," a nurse at the Centralized Eligibility and Appeals Team (CEAT) reviewed Kelly's and my case and determined that "the Veteran and caregiver do not meet eligibility criteria." We were issued a letter dismissing me from the program.

I have wondered, due to the timing, if this person actually did a thorough review of the reassessment report or if, on the morning of March 23, the CEAT staff hastily ejected a number of program participants, anticipating that the Senate hearing may result in a halt to all impending evaluations.

Regardless, this decision highlighted several issues:

1. **Data Discrepancies**: VBA and VHA records are stored in separate databases, leading to incomplete or incorrect ratings and disability information in the VHA record.

2. **Process Discrepancies**: A thorough VBA assessment, considering extensive evidence from multiple medical sources over a decade, contrasted sharply with a superficial VHA evaluation based on a one-time exam with an examiner unfamiliar with Kelly's needs and limited records review spanning six months.

3. **Outcome Discrepancies**: The VBA examination process identified a need for aid and attendance "to protect the Veteran from the hazards or dangers incident to the Veteran's daily environment." The VBA also determined a rating of incompetency due to "cognitive deficit as of TBI." The VHA reassessment determined that a "daily need for supervision, protection, or instruction for a minimum of six continuous months" did not exist.

4. **Penalizing Stable Needs**: Veterans with stable needs or those receiving private care are disadvantaged in reassessments due to fewer medical records. The lack of frequent doctor visits should not be interpreted as an insignificant need. Veterans with stable needs are less likely to doctor frequently and, therefore, do not have an extensive health record.

5. **Penalizing Access Issues**: VA Montana Healthcare strives to provide service to veterans but faces chronic understaffing and a lack of specialty care providers. Kelly has not seen a VA clinical psychologist, so there are no notes in the VHA system from such a specialist about his cognitive impairments for supervision, protection, and instruction (SPI). Similarly, he has not been seen by a VA occupational therapist to document his physical assistance needs. The neurologist who recommended aid and attendance for Kelly retired this year, transferring his care to the only other VA neurologist in the state, located over 200 miles away. Kelly used to receive care from a VA psychiatrist via telehealth, but she also retired, and his medication management was transferred to a pharmacist via telehealth. Through community care, Kelly receives regular spinal injections from an orthopedic surgeon for mobility and visits a community care

chiropractor for pain and mobility needs. Due to VA staffing challenges and shortages, veterans may not develop comprehensive VA medical records with internal notes regarding ADA or SPI needs. In our case, I believe the lack of a detailed VA medical record in the six months preceding the evaluation worked against us.

6. **VBA Ratings Do Contribute to Program Access**: The only positive outcome from the PCAFC reassessment was that adding Kelly's 70% TBI VBA rating to the VHA data system made him eligible for additional support. In September 2022, a VA Polytrauma/TBI program caseworker contacted us regarding his TBI and offered additional services for which he was eligible. When I explained that his TBI had occurred in 2005, the caseworker was initially surprised that he was only now being identified for needed care. "Better late than never," she said.

Considerations and Recommendations:

1. **Presumptive Need**: By its very nature, aid and attendance and serving as a fiduciary are forms of supervision, protection, and instruction. I believe certain VBA ratings should, by their nature, be presumptive of caregiving needs, such as incompetency, aid and attendance, or housebound status. I believe it would save the VHA a whole lot of time, energy, and expense if it utilized the VBA records as part of its assessment process to eliminate reassessments for veterans with presumptive ratings and conditions.

2. **Threshold of Need**: Define in law that ADL assistance does not need to be "each and every time," as currently stated in the regulation and upheld by a court as an allowable interpretation. The current definition is exceptionally problematic for certain conditions. For example, a diagnosis of neurogenic bowel and treatment for encopresis with constipation and overflow incontinence requires substantial and timely hygiene assistance. However, by their nature, these conditions are episodic and irregular. Similarly, the threshold for supervision, protection, and instruction assistance should be "regular," not "continuous daily care." Requiring "regular" assistance with certain SPI needs to maintain personal safety can also be episodic. For example, acting as a fiduciary involves continuous, regular responsibilities, but not necessarily daily tasks. Likewise, providing care during a seizure episode or dissociative fugue state is continuous but not daily, yet these situations demonstrate a "regular" need for safety and protection assistance.

3. **Costlier or Unavailable Alternatives**: Removing caregivers from PCAFC could lead them to seek more expensive care options for their veterans, including home health aides through Medicare or the VA programs. Utilizing home health aides instead of caregivers exacerbates the significant nationwide shortage of home health aides. In addition, the availability of home health care aides, especially in rural areas, like our town in Montana, which has a population of 68, is none to few.

4. **Reassessment Volume**: Approximately 16,000 people need a new PCAFC reassessment before September 2025. I fear another rushed process will be neither comprehensive nor valid, placing undue emotional strain and stress on veterans and caregivers. I believe reassessments for

PCAFC should not be annual. Instead, reassessments could occur when a veteran's needs change significantly, as determined by a doctor or the PCAFC team.

5. **Comprehensive Evaluations**: Specialists should be involved in reassessments. Medical records from providers outside the VA, whether through community care or private care, should be obtained and considered. Given the high staff turnover within the VA, records may need to be reviewed for a period longer than six months to find the most accurate information.

This May marked 19 years since Kelly's injury. Over these years, I have learned that aging significantly amplifies the challenges faced by people with disabilities. As the brain ages, it naturally undergoes changes that can affect cognitive function, memory, and overall neurological health. In individuals with a traumatic brain injury (TBI), these aging processes can be accelerated, leading to a more rapid decline in cognitive abilities and exacerbating existing neurological issues.

Similarly, the body's physical aging process impacts mobility and other bodily functions. Muscles weaken, joints become stiffer, and the risk of developing chronic conditions grows. These increasing needs make daily activities for people with disabilities more challenging and require continuous, specialized care.

Withdrawing support for disabled veterans with high needs and their caregivers is incomprehensible. As the brain and body age, the need for consistent and comprehensive care for our veterans only intensifies. Removing the critical support systems provided by programs like PCAFC not only jeopardizes the health and well-being of veterans but also places an undue burden on caregivers, making it increasingly difficult to manage these complex and evolving needs.

Thank you for allowing me to share my story. I am happy to answer any questions you may have.