



March 1, 2018

**Statement of
Carrie Stead, Director of Programs, The Independence Fund,
And Caregiver**

Chairwoman Dole, Members of the Committee, thank you for the opportunity to comment on the future of the Program of Comprehensive Assistance for Family Caregivers (PCAFC). I am Carrie Stead, Director of Programs for The Independence Fund, and am a caregiver myself.

The Independence Fund, founded 10 years ago, has provided more than \$50 million in adaptive equipment and support services for catastrophically wounded and seriously disabled Veterans, as well as Caregiver support services for the Caregivers of those wounded and disabled veterans.

Overall, The Independence Fund's greatest concern with the PCAFC program is the apparent lack of standardization throughout the program. We see wide variation not only across Veterans Intergrated Service Networks (VISNs), but even across VA facilities within a VISN, or even a single VA facility itself.

This lack of standardization leads to wide variation in tier classification for similar cases; for what services and support individual Veterans and Caregivers are eligible; and even whether the Caregiver will be allowed to stay in the program or be "graduated."

Because of that lack of standardization, we see VA officials improperly apply the Caregiver eligibility standards, such as they exist, especially in cases of spouse or other family caregivers. VA officials apply improper "rules" in ways like telling Caregivers they cannot have outside employment. We also see it where individual veterans are forced by reviewing VA officials, without warning, to prove they cannot do certain activities, even where an occupational therapy order has not been issued.

The result is a pervasive and underlying presumption on the part of the medical administrators that Veterans or Caregivers are frauds, and need to be "tricked" into displaying their actual, greater, capabilities. Shame on the VA for such tactics.

While not the topic of today's hearing, this Committee is charged with making recommendations on other VA benefits and services that impact families and caregivers. Given

that, the single biggest issue raised by the severely disabled Veterans and Caregivers we serve is the lack of access to timely and quality medical care. While we are uniformly told the clinicians that serve our clients, especially the doctors, are first rate, the medical administration staff that is supposed to support the Veteran in gaining access to that medical care, instead seem to consistently and uniformly act to block timely access.

We've received hundreds of complaints from our clients detailing the bureaucratic roadblocks; local "policies" and "guidance" not based on law, regulation, or printed VA directive; or simply what appears to be simple indifference on the part of the medical administration staff; which hinder, if not stop, Veteran access to the care they need. We've received numerous reports of medical providers repeatedly directing care outside the VA, or not in accordance with current standards of care or formularies, only to be repeatedly denied by the medical administration staff, often without justification or explanation.

Ultimately, this comes down to who is in charge of a Veteran's medical care decisions: the Veteran and his family, or the VA bureaucracy? Our experience is that the individual Veteran and his or her family are consistently denied the opportunity to make that choice themselves. In fact, we often experience an underlying, if unspoken, attitude the Veteran is incompetent to make such medical care decisions. This condescension towards the Veteran is unfortunately shared by many of the largest, and oldest, Veteran service organizations.

We believe the vast majority of Veterans are competent to make medical care decisions, just as they would if they were being served by Medicare or Tricare instead of the VA. We are heartened by the commitment President Trump made to that Veteran empowerment in the campaign. Therefore, we implore this Committee to recommend to the Secretary that he fully support a Veteran's ability to choose his or her health care provider, whether within the VA or in the community. Of note, in the current debate underway in Congress, neither the House or the Senate Veterans Affairs Committee passed bills come close to providing the real healthcare choice the President promised.

Finally, the VA issued a Request for Comments on the Caregiver program, with those comments due last month. The Independence Fund responded to that Request with its own recommendations for further refining the Caregiver program. In the interest of time, I request the attached copy of that Response be included in the record today.

Thank you for the opportunity to discuss this with you today.