Veterans' Family, Caregiver and Survivor (VFCS)

Federal Advisory Committee Minutes

March 29, 2022

12:00 PM – 12:05 PM Opening of the Federal Advisory Committee, Dr. Betty Moseley Brown

Dr. Betty Moseley Brown, VFCS Designated Federal Officer, opened the meeting and presented the rules for this meeting.

Betty informed the group that the chat function was disabled but if anyone had resources or information for the Committee's awareness to email them to veofaca@va.gov and she would make sure this information was distributed to the full Committee. There were two public comments: one was distributed to committee members prior to the meeting, the second will be distributed following the meeting. These were received in accordance with the Notice of Meeting and Betty informed listeners that they can submit 5:00 PM EST via email to veofaca@va.gov.

The meeting minutes from September 23, 2021 were distributed to the committee members with no comments.

Betty announced there was a quorum to carry on business and called on Senator Dole for her introductory remarks.

12:05 PM – 12:15 PM Call to Order/Welcome and Comments, Senator Elizabeth Dole

Senator Elizabeth Dole brought the meeting to order and thanked the members and public for attending. She also thanked the group for their prayers and support since the passing of her husband, Bob. She stated their thoughtfulness meant a lot and strengthened her as she now takes the journey from caregiver to survivor.

Senator Dole highlighted the recent events in Ukraine. She thanked those who represented organizations that are currently working to support Ukrainian refugees. She also stressed the importance of those who are working to support veterans, families, and caregivers who are being impacted by the recent news. The Committee will continue to follow these developments closely and consider ways in which they can be supportive through their work and recommendations moving forward.

Next, Senator Dole thanked the returning Committee members for the great work they have done finalizing the recommendations they sent to the VA last fall. She extended a warm welcome to the new Committee members and asked them to share a few comments with the group.

Senator Dole reminded all of the guiding principles for the Committee's work:

- The Committee is here to represent the network of loved ones supporting America's veterans, and not as advocates for their respective organizations.
- They will rely on evidence-based data to guide their priorities and will not hesitate to tackle very difficult challenges.
- They want to be solutions-focused as they examine the problems and select:
    - those which are urgent,

- those which are solvable,
- and which initiatives will make the biggest impact.

Senator Dole mentioned there have been several developments around the Program of Comprehensive Assistance for Family Caregivers (PCAFC) over the last several months. The widespread concern over Legacy Caregivers dropped from the program led her team to meet with Department of veterans Affairs (VA) leadership. VA Secretary Denis McDonough announced last week that a full review of the program would be conducted by VA Deputy Secretary Donald Remy.

Senator Dole mentioned legislation that was introduced by Representative Julia Brownley earlier this month. This legislation, titled the Elizabeth Dole Home Care Act, takes a holistic approach to caregiver support within the VA by providing respite care to caregivers of veterans enrolled in home care programs, and ensures that caregiver resources are centralized and user friendly. It requires VA to provide a coordinated hand-off for veterans and caregivers denied or discharged from PCAFC to any other program for which they are eligible. A Congressional hearing was held on March 16th and the Elizabeth Dole Foundation CEO Steve Schwab highlighted in his testimony the challenges caregivers are facing with the changes to PCAFC. Senator Dole stated that there is a great deal of bipartisan support for this legislation and unity across the MSO and VSO community for its passage.

Senator Dole thanked Dr. Betty Moseley Brown and the VA team for supporting the work of the Committee year-round and for the wonderful job on-boarding new members. She also thanked her staff at EDF for assisting VA with this process. Senator Dole welcomed VA Deputy Secretary Remy to the Committee to provide an update on information outlined last week, as well as priorities he viewed as important for the Committee.

12:15 PM – 12:35 PM Welcome/Remarks, Donald M. Remy, Deputy Secretary of Veteran Affairs

Deputy Secretary Remy thanked Senator Dole and the Committee for leading this effort and for all the work that they do. He also took a moment to offer his condolences to Senator Dole on the loss of her husband Senator Bob Dole, remarking that he was, "A statesman and soldier who understood what it meant to serve and to give everything one has to a cause that is greater than self." He went on to state that the country is a better place because of all he did.

In honor of National Vietnam War Veterans Day, he thanked all Vietnam veterans for their service and honored Committee member Command Sergeant Major Alfie Alvarado-Ramos. He told the story of how she was denied the opportunity to be a combat medic in Vietnam, yet went on to become the first female Command Sergeant Major at Madigan Hospital in Fort Lewis. He said, "When the nation called, millions of servicemen and women answered the call, then shouldered the burden of a long and unpopular war with immense courage and dignity. Thank you and Welcome Home."

After thanking the committee members for their participation, Deputy Secretary Remy discussed his recent visit to the Jesse Brown VA Medical Center in Chicago. He spoke of his discussions with two veteran caregivers and a veteran who was receiving care. One caregiver was the daughter of a veteran in his 90s and the other was the spouse and caregiver of a two-time Purple Heart recipient and Vietnam Veteran. He reinforced how these stories amplified the importance of this Committee's work, as well as the critical importance of the VA Caregiver Program as consider the implications of our aging veteran population, many of whom are choosing to age in their homes.

One of the caregivers said of her veteran, "he served his country first and now his country is serving him." The other caregiver gave him a children's book, *The Medal with a Heart,* which tells the story of why the Purple Heart was created. She explained the desperation, challenges, and the overwhelming nature of the responsibility that comes with caring for an aging parent and how the Caregiver Program saved her life. He said, "That is what this program is all about, supporting caregivers and family members who support our veterans," and he emphasized his commitment to this group and to the cause.

Deputy Secretary Remy introduced Dr. Colleen Richardson, Executive Director of the Caregiver Program, who is a combat Navy veteran who deployed with the Marines to Iraq and was responsible for the Wounded Warrior Battalion at Camp Pendleton. He said she understands what it means to serve and the physical and psychological damage that might come from serving.

He went on to discuss some of the concerns that dissatisfied veterans and caregivers expressed during the Senate hearing on March 23rd and why the program is of incredible importance. From his perspective, if even one veteran feels dissatisfied, then they need to do better. He reinforced the same message that he shared during the last monthly VA Secretary press conference – that VA intends to do better for veteran caregivers. Deputy Secretary Remy stated that supporting caregivers of veterans is a top priority for him, as well as the Secretary. He said they are working diligently to address concerns, which includes making sound, thoughtful, and clear decisions on criteria and regulations, that will allow for accurate determinations that are in both the veteran and caregiver's best interest. He listed the following requirements for PCAFC decisions:

- Consistent and reliable
- Understandable rationale for the decisions that are made
- Clear "next steps" for veterans if they choose to appeal a decision that they disagree with
- A simple process so that veterans and caregivers can get the appropriate care and resources
- Consistent with the intended direction of the *MISSION Act* from Congress

Deputy Secretary Remy also reiterated that the VA will not remove any Legacy applicants/participants from the program or decrease any support before the administration engages in the reexamination of the current eligibility criteria, and where necessary, consider making any changes. He said he looks forward to the Committee's ideas and advice, as well as working with them to better serve veterans and their caregivers. Finally, he reiterated VA's commitment to the continued expansion of the PCAFC program. He then thanked the group for their partnership and opened the floor to questions.

Questions:

Senator Dole mentioned the emotional testimony from caregivers in the hearing who had significant setbacks because of the lack of customer service and uniformity. On behalf of the Committee, she asked for reassurance that there will be a focus on reforming the evaluation model. Deputy Secretary Remy assured the Committee that the VA will engage the field and evaluate eligibility for the program, and that they will be mindful of the challenges that were described during the hearing.

Lee Woodruff asked Deputy Secretary Remy questions that involved repairing trust with VA. She asked how VA will communicate with the community about changes, how the Department will make these changes permanent, and how VA will ensure readiness through comprehensive benefits. Remy emphasized that building back trust is critical and is something that must be done together. Remy

emphasized the importance of working with stakeholders to ensure that any policies or practices that are modified are done in a team effort, regardless of how VA operated in the past. As for the question around benefit design, it becomes more complicated as this issue involves authorities from Congress and the courts, but VA committed to leveraging all of the tools available to deliver this program in a way that is efficient, reliable, consistent, and trustworthy. As VA examines the tools at their disposal, they may be able to use some of the tools that have not been directed to the program before. However, Remy is mindful that the program is created and authorized by Congress and that there is ongoing litigation that has impacted how the program is delivered.

Lee Woodruff expressed that she is looking forward to VA making a difference and that a voice is greatly needed for our veteran families. She thanked Deputy Secretary Remy for his commitment to working with the Committee to address this issue.

Jenna Dorn asked Remy how VA will ensure that there will be consistency across culture and programs within VA, and how he will be involved in the process. Deputy Secretary Remy stated the Committee has his commitment and the Secretary's commitment to remain involved. He explained that the Committee has a great leadership team that has heard the concerns expressed and is prepared to drive us into the future. He wanted them to provide their ideas but also hold them accountable as they look to trying to remedy some of the challenges of the past and build for a better future.

Melissa Comeau asked how VA is going to incorporate the voices of the caregivers into the human-centered design of this program. Remy replied that VA has one of the greatest customer experience-focused teams anywhere in the government and across most of private industry. They understand what the stakeholders' needs are, and deploy resources through surveys, engagements, conversations, and data analysis to ensure the Department is meeting those needs. John Boerstler and his team have been charged with making sure this process is veteran- and caregiver-centric, taking the human-centered design focus that has been put into everything the VA does and assuring it is part of the caregiver support program as well.

Senator Dole thanked Deputy Secretary Remy for spending time with them and answering all their questions.

Senator Dole introduced Margaret (Meg) Kabat, Senior Advisor to the VA Secretary for Families, Caregivers and Survivors, to provide updates on several important priorities.

12:35 PM – 1:05 PM Update from Senior Advisor, Margaret Meg Kabat

Meg Kabat reiterated that the Secretary and Deputy Secretary are more closely involved with the changes to PCAFC than previous administrations. She believes that VA will be able to gain trust back, which has not been an easy task. She presented updates from the Office of the Secretary:

Expansion of Home and Community-Based Services

- Available at all VA Medical Centers by the end of Fiscal Year (FY) 2026
    - 58 Medical Foster Homes
    - 70 Veteran Directed Care Programs
        - Programs in which the veteran and their family receive a budget and then work to spend that budget for either direct care services, respite, transportation, other

services that allow them to remain at home. These programs also provide caregivers with additional support and resources.
    - 75 Home-Based Primary Teams
        - Clinical teams go into the home and provide primary care, occupational therapy, physical therapy.
- Veterans Eligible for Nursing Home Care
    - The aging veteran population is a top priority, especially as the population is projected to double in the next 20 years to an estimated four million.
- Focus on the veteran's role as a member of a family.
    - Focus on veteran's role in families as caregivers, parents, and grandparents who are raising grandchildren.
    - Support to families beyond what VA already does, such as connecting them to community resources or services within VHA/VBA/NCA.
    - Ensuring VA facilities are "family-friendly" and reviewing things like waiting areas and outreach events.
    - Investing in Local and National Partnerships.
- Family Coordinator Program
    - Goal: Have policies in place by the end of the fiscal year and begin piloting the program to 10 or more sites that will have family coordinators established to collect information on lessons learned.

Caregivers

- National Strategy for Family Caregivers
    - VA has an active role in developing the national strategy for family caregivers with the support of Health and Human Services (HHS).
    - HHS recently published a report on and VA is utilizing the data to develop a specific national strategy to better support the caregivers of veterans.
- VHA's Caregiver Support Program
- Interagency Work
    - Joining Forces: First Lady Dr. Biden's program is designed to support families of active-duty service members, National Guard, Reserves, and veterans. Joining Forces is focused on the following salient issues:
        - Food insecurity
        - Spousal Employment
        - Children in Caregiving Families
    - Disability
        - Long Term Services and Support Program (LTSSS)

Survivors

- VA hosts a survivor forum several times a year to provide information on services, support, and benefits for which they are eligible.
- National Cemetery Administration's (NCA) work to expand the Veteran's Legacy Program
    - Colleges and universities are working with their local VA NCA to collaborate on projects to honor the legacy of veterans, such as creating biographies and illustrating the history of those who are buried in the local cemetery.

        - For example, Texas Tech is conducting geo-mapping to help families navigate cemeteries and find their loved one's gravesite.
- Veteran's Legacy Memorial
    - This program is an online space where survivors, family members, and friends can add content to a page for a veteran who is buried in one of the national cemeteries. Recently, it has been expanded to include veterans who are buried in state veteran cemeteries.
- Journey Map
    - VA is planning on developing a caregiver to survivor Journey Map to guide survivors through their shift.

Questions:

Lee Woodruff expressed her hope that this program will improve and asked if VA will consider the recommendations that the Committee put forward last year. She also asked about how VA will be engaging families and receiving feedback from them. Ms. Kabat deferred to John Boerstler for an answer since he will be joining to talk specifically about the recommendations later. She agreed that VA needs to hear directly from the caregivers and stressed that VA is continuing to work on differentiating the needs of various groups of caregivers.

She then briefed the Committee on the Asset and Infrastructure Review (AIR) Commission. The AIR Commission was a part of the MISSION Act and required VA to use evidence-based data driven processes to identify ways to improve and augment VA's infrastructure. This commission is researching the locations of facilities, types of facilities, and facilities that will be needed in the future. The results of the Commission were published in the Federal Register.

Questions:

Melissa Comeau expressed gratitude for VA investing in medical foster homes and asked if VA is funding the program. Ms. Kabat replied that under the current legislation, VA is not authorized to fund the program. Currently, it is well coordinated with the local medical centers and provides more care than a group home alternative.

Ms. Comeau also asked about the expansion of Veteran-Directed Care, and whether or not facilities were still allowed to opt out of providing this service. Ms. Kabat explained that though she did not have the answer to that specific question, she knows that VA is taking into consideration the concerns of medical facilities. She cited confusion over who the program is designed for and concern over the cost.

Finally, Ms. Comeau asked if VA is thinking of including veterans who are survivors in family coordination. Ms. Kabat noted that VA is looking into this and hoping to include this group.

Senator Dole thanked Meg for her comprehensive update and looks forward to great progress over the coming year.

1:05 PM – 1:35 PM Update from the Veterans Experience Office, John Boerstler

Senator Dole welcomed the Chief Veterans Experience Officer, John Boerstler, to brief the Committee on the status of the recommendations from last September and other updates from the Veterans Experience Office (VEO).

John Boerstler thanked Senator Dole for the introduction and was hopeful they would be able to meet in-person soon. He will be providing updates on the recommendations, comment on some questions that were brought up, and will discuss how his office is working on improving the customer-experience (CX) for the caregiver support program.

He also wanted to acknowledge National Vietnam War Veterans Commemoration Day and informed the Committee that VA senior staff have been calling Vietnam Veterans to thank them for their service. This was greatly appreciated by the veterans and their caregivers.

Next, he discussed Human-Centered Design (HCD). VA uses data, tools, technology, and engagement to better inform and improve the customer experience. He emphasized that decisions made by VHA, VBA, and NCA are informed by the voice of veterans, caregivers, and survivors. VEO has the method to inform them of veteran feedback and wants to continue to improve this process for other offices. Mr. Boerstler also discussed the 2019 relaunch of the human-centered design studies, particularly on their caregiver programming at VA. There has been a lot of progress made within the caregiver programs, and VEO wants to ensure that they are capturing the trends that have resulted from these changes. He hopes to use this data to better inform the process going forward and ensure that VA's programs remain customer-focused.

Finally, Mr. Boerstler informed the Committee that the recommendations are almost completed and will be signed soon. Once Secretary McDonough signs off on them, the Committee will receive VA's official responses. He appreciated the Committee's patience with VA's process of ensuring the recommendations are compliant with regulations and laws.

Questions:

Senator Dole asked if the Committee could help to expedite these recommendations. John Boerstler expressed that the Committee cannot help to expedite these recommendations. Mr. Boerstler explained that by having this Committee meeting, the public will be reminded that VA is ready to send those recommendations as soon as they are approved.

Ms. Woodruff asked if the Committee could be one of the stakeholders that receives the research and data. Mr. Boerstler assured Ms. Woodruff that the Committee could be a stakeholder that receives the research and data. Mr. Boerstler thought VEO could report to the subcommittees and the committee-at-large every quarter. This report would include the insights that are captured on the qualitative data and once the surveys are up-and-running, VEO could show them where the "needle is moving," what the trends are, and what makes up the qualitative feedback. Ms. Comeau wanted confirmation that the surveys are going to take place throughout the application, assessment, and appeals process and wanted more information of how the VA planned on including existing and current attitudes towards veteran care. Mr. Boerstler reassured her that inclusion of the current state related to a veteran's care will be included, whether it is on the benefits application, the appeals process, or the care delivery side. VA assured the Committee that they will be monitoring customer feedback.

Dr. Patricia Lester expressed her excitement in the level of engagement and input from stakeholders. She was curious about mapping out family experience and getting feedback from caregivers and veterans. She asked if there was an opportunity to also collect from the youth voice in this process as they think about the children as caregivers and understanding their journey. She expressed that this feedback could help in some of the family coordination programming and Family Centered Design. Mr. Boerstler responded that was a question posed to the Committee in September and that VA is addressing that in their recommendation response. Mr. Boerstler explained that there are opportunities to look at different

customer types to make sure they are tracking experience, but expressed that VA needs to investigate what their authorities and resources are, to be able to conduct those interviews as well.

Alfie Alvarado-Ramos commented that collecting information from the youth voice, as Patricia mentioned, would be good. Since many veteran children end up serving in the military, any experience they have from being a caregiver would be beneficial to the military. Mr. Boerstler reiterated that work had been done in 2019 to develop those personas and, depending on VA's authority and capacity, VA could explore redeveloping these personas around the different customer types. This could include further developing the personas to include youth, as they are scoping the work with the design team.

James Beamesderfer referred to the trust question about the Legacy caregivers who are going to be reinstated. Mr. Beamesderfer asked, how is that going to happen and what is that experience going to be like. Mr. Beamesderfer expressed that this may be an opportunity to not only correct a wrong but also regain trust.

Response: Mr. Boerstler explained the government's most important currency for experience is trust. Unlike the private sector which can rely on Net Promoter Scores and other measurements, the government's Net Promoter Score is built on trust. Mr. Boerstler provided the example of Likert Scale surveys in which one is posed with responding agree or strongly agree based on their experience. Mr. Boerstler further expressed that trust is the North Star in everything VA does. In the Veteran Experience Office (VEO) they measure the "Three E's" along the spectrum across the entire enterprise. All those insights are put into our trust scores and, hopefully, over time show an increase in trust among the community of caregivers, families and survivors that take care of our veterans. The "Three E's" are known as the following:

- **Ease**: Was it easy for me to park at a facility? Was it easy for me to digitally access a Veteran Service Representative?
- **Effectiveness**: When applying for benefits was the process understood when digitally filing a claim or submitting this through a VSO?
- **Emotion**: When receiving information from my clinical provider about my care, did I feel respected in that encounter?

Senator Elizabeth Dole thanked John for these important updates, and she expressed her appreciation for all that he is doing to serve veterans and their families.

1:50 PM – 2:20 PM Program of Comprehensive Assistance for Family Caregivers (PCAFC) Expansion, Dr. Colleen Richardson, Executive Director, VA Office of Caregiver Support

Senator Dole welcomed Dr. Colleen Richardson, the Executive Director of the VA Office of Caregiver Support, to brief the Committee on the recent pause of PCAFC. Senator Dole asked Dr. Richardson for an update on how VA is engaging the community to develop new regulations, determine eligibility formulas, and reform the evaluation process.

Starting with PCAFC, Dr. Richardson informed the Committee that the Caregiver Support Program (CSP) is prepared to go forward with the expansion to veterans and caregivers of all service eras on October 1, 2022. CSP is engaged in conducting reassessments of Legacy applicants, Legacy participants, and their family caregivers. The program office is actively collecting data on the reassessment outcomes to evaluate the need for regulatory changes. She reaffirmed that VA will not be taking any action on reassessment determinations involving Legacy participants, unless they are eligible for an increased

benefit. Additionally, CSP is implementing expanded appeal options for veterans and caregivers who disagree with a PCAFC decision. Appeal options for veterans include VHA Clinical Appeals Process, Supplemental Claim, Higher Level Review, and Appeals to the Board of Veteran Appeals.

Dr. Richardson emphasized that VA wants to be holistic in their approach and "get this right." As a combat veteran, she knows that VA has its challenges and has experienced them first-hand in her personal care. She recognizes that these regulations were developed years ago and have been met with great frustration from the community. She wants to work with the Committee to address these key problem areas and work together toward a better, more equitable program without further delaying expansion.

Next, Dr. Richardson addressed the Legacy reassessments for applicants and participants. She has heard feedback that the process is dehumanizing, exhausting, and not veteran and caregiver centric. She was also informed that the wellness contacts were taking too much time and not meeting the intended purpose. To address this, CSP modified the wellness contacts so they only take five minutes to check in with caregivers and offer resources as needed. CSP will continue Legacy reassessments to gather information and make better informed decisions as they move forward. Reassessments are also being completed to determine if veterans and caregivers may need a higher stipend level or a higher level of clinical care.

CSP is also working on new options for veterans to appeal their decisions. These new options change the way veterans and caregivers can appeal decisions that they disagree with within PCAFC. Today, veterans and caregivers can now appeal those decisions through the VHA clinical review/clinical appeals process, the Board of Veterans Appeals, or through a higher-level review. The Caregiver Support Program Office has begun reviewing the new appeals and will be leveraging staff within VBA as well as the Board of Veterans Appeals (BVA), OIT, and several other agencies to help.

Dr. Richardson updated the Committee on the most recent data from PCAFC:

- 140,000 applications received after Phase 1 expansion
- 74% of applications are processed under 90 days
- Applications that need advancing based on veteran illness or injury were expedited
- CSP currently has under 9,000 pending applications. This is a decrease from 32,000 last month
- Received over 18,000 applications in the first month after expansion, and they anticipate a large number of applications after the second expansion in October 2022
- The Caregiver Support Line (CSL) has received over 86,000 phone calls resulting in referrals to the caregiver support coordinators at local VA medical facilities

Dr. Richardson provided updates regarding the next steps following the pause on PCAFC removals. She noted that VA will suspend discharges of any Legacy Participant, Applicant and their Family Caregiver from the Program of Comprehensive Assistance for Family Caregivers (PCAFC) because of eligibility criteria changes enacted as part of the MISSION ACT of 2018, (per DEPSEC press release of 5/22/2022). The Caregiver Support Program will continue reassessments to gather additional data to inform future decisions. VA will not be taking any action on reassessment determinations involving Legacy participants – except those eligible for enhanced benefit. Recipients can appeal if they are currently Tier 1 but feel they need to be Tier 2 dating back to October 2021.

In order to gather feedback and information from the community, VA will convene an external stakeholder engagement "summit" with Veteran Service Organizations, Members of Congress, veterans, caregivers, and other relevant stakeholders. The goal of this summit is to work with the community on how the program can be improved and determine a strategy for moving forward. CSP will be collaborating with the Veteran Experience Office to develop and administer a human-centered design survey to measure customer experience.

Dr. Richardson briefly discussed the Legal and Financial Planning Services. The program was planned for implementation during the last fiscal year, but it was not yet the appropriate quality for veterans and caregivers. Currently, there is a solicitation out for contracts and VA hopes to have it awarded by this fall to revise the criteria to better meet the needs of veterans and caregivers.

Dr. Richardson explained that though she does not have all the answers for the questions regarding Legacy applicants, participants, and family caregivers, she emphasized that her office is taking them into consideration as they move forward. Lastly, she shared that approximately 8,640 active family caregivers in the PCAFC program have received one or more doses of the COVID-19 vaccine through VA and 8,440 active family caregivers are fully vaccinated for COVID-19 through VA.

Questions:

Senator Elizabeth Dole thanked Colleen for these important updates and stated the Committee will work closely with her every step of the way. Senator Dole then asked Dr. Richardson what the timeline would be for VA to answer the questions the community has posed, especially from those negatively impacted. Dr. Richardson explained that she did not have all the answers yet, but hoped to have those questions answered by the following week. Dr. Richardson further explained that VA is working diligently at the enterprise level given these actions impact many organizations and communities across the board. Dr. Richardson will notify the committee as soon as VA has established a timeframe.
Dr. Bob Koffman thanked Dr. Richardson for an important presentation. He explained that veterans are having an increased population of cancers and that there is some causation in terms of toxic exposure recognizing that many of these cancers take years to develop. Dr. Bob Koffman asked Dr. Richardson how she evaluates the utility of the cancer registries in terms of identifying legacy veterans who may have cancers associated with their service. Dr. Richardson responded that she was not aware that they were currently using the cancer registries, but VA needs to be aware of those veterans who need intermittent care. While veterans may not meet the requirements of six months or longer, Dr. Richardson noted that toxic exposure is an issue, and this is a group of veterans that her Field Operations Team has identified as a group they were missing and need to take into consideration as they move forward.

Ms. Woodruff thanked Dr. Richardson for addressing the fact that there is work to be done within the veteran population and that the work is appreciated. Ms. Woodruff explained there are many veterans that fall into the category of invisible injuries such as brain injury and PTSD which can vary depending on the day. Ms. Woodruff hoped these invisible injuries would be considered when reevaluating the eligibility requirements for PCAFC. Ms. Woodruff asked what the caregiver program may consider doing for those with invisible wounds. Dr. Richardson responded that there is a difference in instruction of supervision and protection between the pre-1975 and post-9/11 veterans. She further explained that the need for differing instructions is identified and there is an opportunity for VA to do a better job of helping caregivers who care for those veterans with invisible injuries. Dr. Richardson also said there are treatment options available to help veterans and caregivers, however, some veterans will never recover from certain injuries, and she wants to make sure this program is available and that she is able to talk to those veterans and their caregivers about options, especially clinical options. Dr. Richarson recognized a need for better education and training around the SPI portion and also, a focus on identifying those needs to make sure we are getting veterans and caregivers the appropriate resources.

Jenna Dorn asked if there may be a bias against those with invisible wounds of war in eligibility and treatment because it is more difficult to identify and treat those invisible wounds and what steps could the program take to address the needs of those who have invisible wounds. Dr. Richardson said she believes the eligibility regulations were developed and written as to meet the intent of Congress at the time and that the previously identified gaps in the old regulations were addressed. However, there are still gaps of

consistency, standardization, and equitability, and many in the community have mentioned these concerns. Dr. Richardson said there are opportunities to reevaluate and do a better job as the program moves forward. She emphasized that listening to caregivers and their recommendations is a must when addressing gaps and destigmatizing these invisible injuries.

Melissa Comeau asked about the hold on supplemental claims and whether they were being held because VA wants to make sure they are doing them right before they are acted upon. Dr. Richardson clarified that when she said "hold" she meant a situation similar to the Veterans Appeals Improvement and Modernization Act of 2017 (AMA) supplemental claims reviews. She stated she is in the process of hiring 70 additional staff to complete those reviews within the program office, and confirmed, they are actionable through her office.

Ms. Comeau asked how the reassessment of caregiver status in the caregiver program affects their home care if the caregivers are also getting home healthcare. Dr. Richardson was not sure and asked if Melissa had a suggestion or feedback to provide as she would be open to hearing this. Ms. Comeau has sensed from the community that if a veteran is eligible for one, they might not be eligible for the other. It seems unclear as to what the home healthcare eligibility along with caregiver support eligibility is and if they interact. Dr. Richardson explained that VA is not duplicating services. She provided an example; if VA is paying caregivers to perform a certain service, they try not to duplicate that effort by either doing Veteran-Directed Care (VDC) or homemaker home health aide, etc. There is a case mix tool series that they use with Geriatrics and Extended Care (GEC) to identify both needs and make decisions, then inform the veterans and caregivers of that duplication and offer them options. Veterans and caregivers can then decide how they would like to go about the next steps. Dr. Richardson also mentioned that there may be some room for improvement.

Ms. Comeau asked various questions regarding Legacy participants and asked whether VA is looking at any of those caregivers who may have applied and had been denied and that under this reassessment VA could look at those that were initially denied vs. those just being reassessed. Dr. Richardson stated that is absolutely a possibility.

Senator Dole thanked Dr. Richardson and expressed how critical it was to be proactive in communicating directly with caregivers and the organizations that support them.

2:20 PM – 2:35 PM Children and Youth as Caregivers, Steve Schwab, CEO Elizabeth Dole Foundation

Senator Dole introduced Steve Schwab, CEO of the Elizabeth Dole Foundation, to present on the children and youth caregivers of veterans, also known as Hidden Helpers. This subject has been extensively discussed by the Committee, with a focus on their caregiving responsibilities that scope far beyond the normal experience of children their age. Steve thanked Senator Dole and emphasized that this topic was born out of this Committee's recommendations.

In 2017, EDF commissioned a RAND study to develop a research blueprint to improve support for military and veteran caregivers. The Committee's interest in understanding the remaining gaps in research led to the establishment of the Elizabeth Dole Center of Excellence for Veteran and Caregiver Research.

This study highlighted the need for research that specifically examines how well programs for caregivers and care recipients were working, how caregiving affects specific subgroups, including children, and how caregivers and care recipient needs evolve over time. The report found that there have been no published studies examining the impact of caregiving on military children. In response to these findings, EDF began

preliminary research to identify the prevalence of children caregivers, the tasks they participate in, and assess psychological, behavioral, and academic outcomes. This carved a path for what would become the comprehensive Mathematica study.

In November 2021, the EDF stood at the White House with a national coalition of over 60 organizations to identify the gaps in support for children and youth, referred to as "Hidden Helpers." Mr. Schwab addressed the findings of this groundbreaking study:

Who are Hidden Helpers?

- Children and adolescents with a wounded, ill, or injured veteran parent or guardian.
- 2.3 million children under the age of 18 living and helping care for a veteran who is disabled, emotionally, mentally, or physically.
- The children's life is unlike their peers because caregiving consumes time and energy especially for older children.
- For the parents and older siblings, they are also caregivers and not able to provide as much development oversight for the younger children which can lead to negative impacts on the children's developmental life cycle.

Hidden Helpers are more likely to:

- Take on roles that are far beyond their developmental capabilities.
- Experience isolation and have fewer opportunities to interact with peers. The responsibility of taking care of their mom, dad, brother, or sister may prevent children from playing with their friends.
- Have difficulties expressing emotion.
- Face challenges learning in school because of their environment at home.
- Have more health challenges such as high levels of stress, burnout, and fatigue.

These were many of the same headlines they saw in their first study with RAND that was released in 2014 with First Lady Michelle Obama and, then Second Lady, Dr. Biden. Adult caregivers also experience many of the symptoms found in Hidden Helpers, though the impact of caregiving on children may have severe implications in later years.

EDF commissioned an independent research agent, Mathematica, to answer critical questions around how the Foundation and VA can develop datasets, quality programs, and interventions to adequately assist Hidden Helpers. The research recommended the following:

- **Develop quality programs and interventions** supporting children in caregiving families focused on peer support, mental health, and age-appropriate developmental opportunities.
- **Fund, promote, and create** supports for the entire family unit. More holistic approach to how they are supporting this population.
- **Amplify national campaigns** aimed at improved understanding of veteran's wounds, the needs of caregivers and children in caregiving homes.
- **Partner to reduce barriers** to health care and provide centralized comprehensive services focused on supporting caregiving families. Work with our VA, DoD, and system partners at the national level.

In anticipation of Mathematica's findings, EDF proactively build a coalition of leaders across the space, representing health care, education, philanthropy, youth development, family functioning, and many more. With more than 60 partners, EDF sought commitments and focused on preparing coalition members to jump into action quickly to address challenges identified in the research. Currently, the

coalition includes the Wounded Warrior Project (WWP), National Military Family Association (NMFA), the American Red Cross, and the White House.

The VA has committed to implementing a Family Coordinator program with social workers linking veterans and support for their spouses and/or children. The Family Coordinator will be able to provide information about resources in the local community and the federal government to support veterans and their families. Currently, VA's Elizabeth Dole Center of Excellence for Veteran and Caregiver Research is collecting qualitative data on the lived experiences of parents and youth who live in veteran caregiving households. This data will be used to inform the role of the new Family Coordinators.

Mr. Schwab spoke to the power of coalitions and action to address the data in research using a holistic and evidence-based approach. He reiterated that the Hidden Helpers initiatives were established up as a direct response from the Committee. He emphasized that it is time to recognize and support children as caregivers and explore methods of providing them with proper resources. The coalition meets monthly, is growing rapidly, and has resulted in EDF hiring staff to support this program. He concluded the presentation and opened the discussion to questions.

Questions:

Dr. Patricia Lester thanked Steve for his incredible work and asked him to speak more about the Family Coordinator Program. Specifically, the opportunities for early identification of kids who may be having trouble as well as opportunities for routine screening for family well-being and child needs so they would be able to bring resources to match the child's needs in a timely way.

Mr. Schwab said part of the answer was this Committee and VA to build the capabilities, the protocols, and the practices of the Family Coordinator Program to make sure the suggestions of the Committee are carried out. The program is in its infancy, and it is a great commitment the Secretary and this administration are making to address this huge gap in support. As the program progresses, the coalition will figure out the screening pieces mentioned and the indicators that are important. The Family Coordinator Program can help get ahead of early identifiers and trends before they become acute and urgent issues. He said working with the subcommittees developing a protocol and plan to bring to Meg and VA for the next meeting would be a great way to go.

Dr. Lester said she is happy to engage in dialogue offline and there are great opportunities to bring educational prevention strategies and early identification without crossing over that boundary of treatment.

Maggie Walsh asked if he had reached out to Student Veterans of America (SVA) to partner? Mr. Schwab said Student Veterans of America is an important partner on all fronts, but this coalition has not reached out to them yet, but he will. He stated it would be a huge opportunity and thanked Ms. Walsh for mentioning it. Ms. Walsh mentioned that they see many of these young families move to an area of the University they want to attend with the GI Bill and some of these children may be acting as caregivers, but they are often in a new place where they do not have the familiar surroundings they grew up with.

Mr. Schwab agreed that it was a good point, and they will take that up as an action item.

Senator Dole asked Mr. Schwab what the biggest challenge would be in building adequate support for this group of children. Mr. Schwab answered that the biggest challenge was lack of awareness, just as many people did not know about caregivers or the fact they existed. Many do not self-identify as caregivers because they think of themselves as a spouse or loved one who is performing family duties. Then they are introduced to the supports out there and they realize that they need those supports. The same is true of

these children and even more challenging because they are children. The first hurdle is finding the children where they are and where they need these services and support to build this sense of awareness and recognition. The second hurdle is ensuring that we can deliver timely and available services before they reach the acute stage, the urgent stage as well as before it becomes a huge impact to their schooling. The challenges are twofold around awareness and then getting to these family's timely services and supports before these problems become urgent. They divided the coalition into committees and some of what is being discussed today can be brought back to the committees as action items.

Ms. Comeau said a family coordinator approach is key. She will take what she learned on this Committee today back to the group that is focused on child peer support. She stated that children need to know that they are not alone and that there are others that have similar experiences. They need a chance to be a kid and talk openly and freely about their experiences. She also mentioned college-age caregivers who have deferred college because of their caregiving responsibilities.

Ms. Woodruff mentioned that Student Veterans of America probably have siblings so she can see a ripple effect to other age groups. She asked for a summary of what was heard today. She mentioned that there has been an 80-90% rejection rate and although they are "on pause" there is $1.5 billion dollars in the program and more that looks like it was just committed by the Secretary. From the caregiver support services, she looks at caregiving support as preventive medicine. If VA helps pay for these services helping families be in the home instead of institutionalization is important. She is passionate about hidden injuries and making sure families get the compensation they need. And although they heard all the "right stuff" today, she wanted to know where we are.

Mr. Schwab responded that he agreed that they have heard a lot of things in this committee, there are copious notes taken as the proceedings continue. One thing that could be done is to do a little bit of level setting at the end based on the notes. He mentioned he could offer to quickly send a summary out and that he would check with the Senator. There needs to be action items and he believes the Committee can keep these topics on the "straight and narrow" when it comes to making sure the families are taken care of.

Senator Dole thanked Steve and Mike Linnington from the Wounded Warrior Project for serving as the co-chair on this national effort.

2:35 PM – 2:55 PM Caregiver to Survivor Briefing, Bonnie Carroll- President, Tragedy Assistance Program for Survivors (TAPS) and Melissa Comeau-Director, Red Cross, Military and Veteran Caregiver Network

Senator Dole expressed the Committee's eagerness to hear from Bonnie and Melissa on the partnership with EDF to build a road map for those transitioning from caregiver to survivor. She shared her own recent experience with loss and the importance of advocating and advancing the needs of all family members, wherever they might be on their caregiving journey.

Bonnie Carroll thanked Senator Dole and expressed her condolences for the loss of her husband. The Committee is dedicated to ensuring all veteran caregivers who become survivors receive the resources and care they deserve, and she thanked Senator Dole for the opportunity to serve in the caregiver to survivor partnership with the Elizabeth Dole Foundation. The Military and Veteran Caregiver Network of the American Red Cross and the Tragedy Assistance Program for Survivors (TAPS) was formed in response to a request from this Committee to address the increasing number of military and veteran survivors who were caregivers prior to their loss, and to better understand the full range of their experiences both before and after their loved ones' death.

The TAPS Illness Loss Survivor Survey was used extensively along with four focus groups of caregiver survivors to capture their experience and collect invaluable qualitative data on the needs, challenges, services, and resources that helped them most. They reviewed research on interventions that support caregiver survivors to identify proven practices to better inform the delivery of caregiver survivor support. With assistance from the Elizabeth Dole Center of Excellence and the feedback from the focus groups, they are now able to recommend changes to policies, programs, and practices to best support caregiver survivors.

In 2021, military survivors reported the death of a military loved one due to illness (31%), suicide (27%), and hostile action (4%). 9,246 newly bereaved military and veteran survivors came to TAPS for care in 2021 from all services and all eras. TAPS can presume that most of these new bereaved survivors were also caregivers prior to their loss. Also, 1,169 of the youngest survivors, the children, were provided with critical support through specially tailored programs and events.

VA anticipates that more veterans with potential toxic exposure illnesses and cancers will require care. The caregivers will need support throughout their journey, and many will need support as survivors as this population continues to grow. Survivors of all ages find that their health has been impacted by their care responsibilities, even before they experience the grief and bereavement of a loved one's death. Survivors will often find themselves grieving their loss while they continue to care for other family members. Adult survivors are increasingly requesting professional mental health support for surviving children who are grieving a death due to an illness or suicide.

Recommendations to assist caregivers becoming survivors:

- Conduct an assessment of both the caregiver and care recipient to create a customized, comprehensive, and evolving support plan before and after death.
- Provide potential caregiver survivors with timely, clear information and training for their multiple roles (e.g., caring, parental, legal, financial).
- Streamline benefits applications and appeals processes. Removing inequities in eligibility by era, rating, type or location of death.
- Increase the awareness of, and connection to, the full range of relevant resources and services, including bereavement interventions.
- Ensure availability of peer grief support services for caregiver survivors of all ages and those most at risk (e.g., suicide).

Ms. Comeau explained that the research on bereavement experiences and specific helpful interventions is limited. There is a mismatch between survivors reported needs and studied interventions, whereas interventions tend to be narrow but multidimensional interventions tend to target just individuals. There is the need for a family approach and interventions that vary by the types of survivors. Needs and circumstances are understudied, and the data surrounding outcomes are limited and tend to rely on self-reporting. Evidence suggests that intervening early leads to better outcomes and peer support interventions are particularly helpful for suicide survivors.

Ms. Comeau thanked the group and asked if there were any questions.

Questions:

Senator Dole asked Bonnie Carroll about the most immediate steps the Committee needs to take to support their work. Ms. Carroll replied adopting those recommendations outlined particularly now with the support of the Secretary and administration. She is grateful that they had the opportunity to do the

kind of research that has allowed the caregiver survivors to have a voice and express the critical, most urgent needs.

Senator Dole thanked them and reiterated the importance of this critical mission supporting their community throughout this transition. She then asked Steve to quickly level set them on what was heard today.

2:55 PM – 3:00 PM - Wrap up and Adjourn, Steve Schwab and Senator Elizabeth Dole

Steve Schwab wanted to acknowledge again and thank Dr. Betty Moseley Brown for her hard work. He also thanked the public, especially those from the caregiving family and survivor community, who joined to listen to the discussion. He provided some quick headlines from the discussion and is looking forward to working with the Committee.

The level set is that we heard from VA, a strong commitment to what was heard from VA last week in "word" now happening in "deed" and that Deputy Secretary Remy, Dr. Richardson, and Meg Kabat are going to work closely with this group to ensure the Committee can navigate through this process and to ensure the community they will stay close to this to make sure that it happens.

Senator Dole thanked Mr. Schwab for the summary. She expressed her delight with the robust discussion and is looking forward to working with the Committee over the next two years on thoughtful and comprehensive solutions.

Next, she explained that they will divide into two subcommittees that will work to study issues, discuss different topics, and begin to formulate recommendations that can be considered at the next meeting. Bonnie Carroll and Lee Woodruff have been asked to continue chairing the two subcommittees with the following assignments:

- Families and Caregivers Subcommittee: Lee Woodruff, Melissa Comeau, Sherman Gillums, Jenna Dorn, Mike Linnington, Hollyanne Milley, Trisha Lester, Becky Porter, Marissa Owen, and Jim Beamesderfer.
- Survivors Subcommittee: Bonnie Carroll, Alfie Alvarado Ramos, Gabby Kubinyi, Bob Koffman, Paula Cobb, Robert Thomas, Lauren Trosclair Duncan, and Maggie Walsh.

Senator Dole concluded by thanking the group for their commitment and passion for their vital work together.

Elizabeth Dole

Senator Elizabeth Dole, Chair

Betty Moseley Brown 6/29/2022

Betty Moseley Brown, EdD
Designated Federal Official