Department of Veterans Affairs

Veterans' Families, Caregivers, and Survivors Federal Advisory Committee Meeting

March 1 – March 2, 2018

Attendees:

Committee Members Present:
Senator Elizabeth Dole, Committee Chair
Sherman Gillums, Committee Vice Chair
Mary "Dubbie" Buckler
Bonnie Carroll
Melissa Comeau
Harriet Dominique
Jennifer Dorn
Ellyn Dunford
Mary Keller, Ed.D
Robert Koffman, MD
Yvonne Riley
Joe Robinson
Loree Sutton, MD
Francisco Urena
Shirley White
Lee Woodruff
Lolita Zinke

Committee Members Absent:
Michael Linnington
Elaine Rogers

Department of Veterans Affairs Staff Presenters:
Lynda Davis, PhD, Chief Veterans Experience Officer
Christine Merna, DFO
Laureen Barone
Laura O'Shea
Chi Szeto

Thursday, March 1, 2018

9:05 AM – 9:20 AM Call to Order, Welcome, Opening Remarks *Hon. Elizabeth Dole*	**SUMMARY:** • Sen. Dole welcomed members and thanked them for the excellent work they have done since the last meeting. • Sen Dole shared the agenda for the day outlining presentations from: Dr. Lynda Davis, Veterans Experience Office; Meg Kabat, Caregiver Support Program; Dr. Thomas O'Toole, Choose Home; Margarita Devlin, Benefits Assistance Service; and community partners including UCLA and USC. • Sen. Dole also noted that the subcommittee chairs will provide report outs to share information, to eliminate duplication, and to promote collaboration between and

	among the subcommittees. • The day will conclude with a public comment period, which is the most important part of the Committee's work.
9:05 AM – 9:20 AM Director's Address/ Welcome *James Doelling* *Meghan Flanz* *Heidi Marston*	**SUMMARY:** James Doelling, Associate Director for Patient Care Services at VA's West LA campus • Mr. Doelling welcomed the Committee members, shared some of his background and offered his support. • Committee question: How many caregivers are you supporting at LA campus in your program? o Mr. Doelling responded in the 300s. Meghan Flanz • Ms. Flanz welcomed the Committee and shared some of her background. • Her current position (newly established and appointed in the last five weeks) is to support the Draft Master Plan to develop the north part of the campus. • Ms. Flanz shared some background on the West LA campus including that it started as a home for disabled soldiers from the Civil War and was well maintained through the 1970's. Between the 1970's and now, things have been done that are inconsistent with the land grant and the legal parameters. • There was a lawsuit and a settlement to restore a community on the North Campus for our nation's heroes to gain additional job skills and to heal. There is an enormous problem with homelessness in LA and specifically with Veteran homelessness. The campus is building capacities for homes and supportive services. Heidi Marston • Ms. Marston oversees the Homelessness Program at the West LA campus. • The campus is trying to build a community for Veterans to integrate into normal life. To support this effort, the campus is interested in hearing what the Committee knows/has discovered and things the campus can do to provide services to our Veterans. Dr. Davis • Dr. Davis thanked the West LA team for their hospitality to the Committee over the next couple of days.
9:25 AM – 10:15 AM Insight and Measurement *Dr. Lynda Davis*	**SUMMARY:** • Dr. Davis thanked Sen. Dole and the Committee for the opportunity to share the information in which they have expressed an interest. • Dr. Davis will be talking about the Veteran's Experience Office's (VEO) data collection efforts and feedback collected from Veterans, families, caregivers, and survivors. • Dr. Davis shared her recent personal experience at the West LA Campus' Center for Mental Health. Dr. Davis thanked the Committee for being here and being committed to addressing the challenges our Veterans and caregivers have. Surveys • The VEO has Medallia, a state-of-the-art tool for collecting information, including information from our caregivers and families. • Medallia executes a VA-wide "trust" survey done quarterly. The survey is about the ease of accessing services, the effectiveness of services, emotional experience, and trust. One use of the data is for program improvement. • Service line surveys will allow VEO to go to the next level. VEO is starting with an

outpatient services survey that will show what Veterans are saying.
    - For example, the service line survey will allow VA to look at the operations of a pharmacy in a particular hospital.
    - A digital comment card will allow anyone coming into a Medical Center to provide direct feedback through an app. For example, they can say, "I've been waiting in line for 20 minutes" or other specific information on which the individual wants to comment.
    - This will roll out by the summer 2018.
- Dr. Davis asked the Committee to think about how the surveys can be used.
- Committee question: Do the surveys allow for outreach to ask respondents to provide more details/explanations?
    - Dr. Davis responded yes, they can also be used for service recovery because emails will be provided. VEO is ensuring proper use by working with Office of Management and Budget (OMB) and establishing data governance for when and how to reach back.

Patient Experience (PX) Program

- The PX Program is VEO's effort dedicated to working with the Veterans Health Administration (VHA) to infuse customer experience tools in the hospitals. This effort includes best practices from Cleveland Clinic, Mayo, and the best of the best.
- The Secretary supports this program because, unless our providers are listening, VA won't be effective.
- Committee question: Is there an algorithm for tracking positive comments?
    - Dr. Davis responded there are three topics:
        - 1. Concerns/complaints
        - 2. Compliments
        - 3. Recommendations
- Committee question: Has there been any progress on using these tools for rating providers?
    - Dr. Davis responded that there is no thought for using this as a rating tool for the Veteran or provider right now. It will not be used for compensation or rating providers.
    - VA needs to use the feedback, daily, for program improvement.
- The PX Program includes:
    - Five different tools, with 70% of VA facilities already trained
    - ICARE Rounding
    - Red Coat ambassadors
    - Improved name tags at medical centers
- The PX Program implementation will be wrapped up this year. The Program started in VHA and will take the same approach to customer experience with the Veterans Benefits Administration (VBA).

Welcome Kit

- VEO used Human Centered Design to develop the Welcome Kit to improve understanding of services and benefits and improve navigation. This is in direct response to the feedback and experiences of Veterans and their families. The Welcome Kit is easy to understand and follow.

Committee comments

- Dr. Davis asked for anything the Committee is considering recommending. VA would like to be able to answer and support the Committee with the tools and regulations.

	• Committee comment: We would like staff to extend a thank you for the efforts in support of caregivers, or people taking care of Veterans. For people who feel like they don't do enough for their Veteran, they don't want to hear "you should have done something better." Part of the experience should be reinforcement that people are doing the right thing and be thanked for their time. There's a request for reinforcement to the caregivers that they are doing well. o Dr. Davis responded that this will be part of the PX training. There is another initiative that Meg Kabat's office is engaged in to make sure providers are sensitized to the role of the caregiver. o Senator Dole responded that USAA has an effort to make sure the caregiver is part of the team and is in the treatment room at all times. This will be a massive cultural change at VA. • Committee question: The Welcome Kit doesn't mention caregivers. Can one of these significant points be recognizing the caregiver as part of the Veteran's team and support services? Also, maybe build it in to "taking care of yourself." o Dr. Davis responded that she recommends it be added as an insert or sheet about the caregiver. o The audience responded that they recommend going further and adding it to the Welcome Kit when it's reprinted. • Committee question: After many years and many dollars of trying to upgrade the IT system, VA is going to the same system the Department of Defense (DoD) uses. Can Dr. Davis comment on this? Applying for a disability rating may trigger Post Traumatic Stress Disorder (PTSD) knowing how long it takes. o Dr. Davis commented that VEO is working in collaboration with the IT effort as it has to be informed by the experience of the Veterans and caregivers. VEO is working with the effort to design the questions and hope it will be more successful than the past ones. o Separately, there are things that can be done right away to change the awareness that providers have of the important role of the caregiver, family members, or survivors and how they respond to integrating them into the conversation. • Committee question: In the surveys, is it specified whether a respondent is a family member, caregiver, or survivor? Is that an option? o Dr. Davis responded that the survey is currently only for the Veteran. However, it can be looked at in terms of different ways of serving them. o The audience responded that they agree, but they are the ones to complete the surveys that are sent to their spouses. o Dr. Davis responded it would be nice to designate which specific people will be completing the survey. The tool is sophisticated enough to know if the respondent is a third person. It can be assumed some comments are caregiver comments; it's an indirect path. • Committee comment: Adequately capturing comments or inputs of the caregiver is difficult. It could be captured anytime someone calls on behalf of their loved one. They could be asking about VA home loans or education benefits. Recommend capturing the voice of the caregiver is considered as part of the next phase of caregiver feedback. o Dr. Davis responded absolutely, VA is a listening audience. • Senator Dole thanked Dr. Davis.
10:15 AM – 10:30 AM Break	

10:30 AM – 11:15 AM
VA Caregiver Support Program
 	
Meg Kabat
	SUMMARY:
	Caregiver Support Program
	• Ms. Kabat provided a high-level overview of the Caregiver Support Program, purposefully starting with services offered to all caregivers.
	• Every year VHA does a survey of all Veterans, and the Caregiver Support Program had an opportunity to add questions about caregivers to get a sense of how many Veterans receive caregiver help.
	• 2.4M Veterans, or 27 percent, receive some level of support or assistance from caregivers. This aligns with the RAND Hidden Heroes research.
	• The Caregiver Support Program's mission is to promote the well-being of family caregivers who care for our Veterans through education and services.
	• The Caregiver Support Program was established in 2007.
	• Caregiver Support Coordinators are the heart of our program.
	• There are 350 Caregiver Support Coordinators across the country that are supported at the central office.
	• The Caregiver Support Program offers the following services:
	  ○ Caregiver Support Line
	  ○ Caregiver Website
	  ○ A menu of services to support families
	  ▪ Caregiver Self-Care Course
	  ▪ Caregiver Education calls: an average of 100–115 caregivers per call. Calls are done three times a month with different topics for each call
	  ▪ Peer Support Mentoring: need to strategically use this program and know how to expand it; there are only about 300 participants right now
	  ▪ REACH VA: a caregiver works with a physician to design specific programs to support a Veteran
	  ▪ Caregiver Telephone Support
	  ▪ Building Better Caregivers: funded initially as part of the pilot, there is a contract with Canary Health that provides a series of workshops over six weeks. Caregivers are grouped together with a facilitator; they set a goal and report on the progress. There have been 3,000 participants with great feedback, which sparked an alumni community.
	• The Secretary understands that caregivers need to be supported across all VA programs. It's important the Caregiver Support Program doesn't work in isolation.
	• The Secretary asked Meg if she could help him understand caregivers to Veterans that were serving prior to 9/11. A handout was provided to the Committee that speaks to this. A second handout was provided that speaks to the different services within the Caregiver Support Program.
	• Committee question: What's the coordination and collaboration with partners, such as Blue Star Families? Is there a need to have a formal cooperative agreement?
	  ○ Ms. Kabat responded that there is a lot of coordination. There are some agreements, and Ms. Kabat has a lot of flexibility.
	• Committee comment: Respite care wasn't mentioned; it needs to be considered.
	  ○ Ms. Kabat responded that respite is provided to families in many ways, but it's not part of the Caregiver Support Program. The Caregiver Support Program looks to the strategic partners to help with creative ways to provide respite support; historically there haven't been a lot of opportunities.
	• Committee question: How do you communicate with staff and caregivers?
	  ○ Ms. Kabat responded that it's done in many ways. It's done at the medical centers; caregiver support coordinators help with this. Phone, email, and in

person are all methods of communication used.

- Committee question: At what point does the feedback get exposed that the pharmacy is a major issue with caregivers?
    - Ms. Kabat responded that this issue is being worked. The establishment of this community is helping; it's not just the Caregiver Support Program saying caregiver support needs to be integrated in everything the Program does. The Program needs to get to a point where help is provided to pharmacy to understand what the challenges are for caregivers.
- Committee question: What's the Program's way of reaching out to charities and non-profits?
    - Ms. Kabat responded that with most medical centers it works well because there are local representatives that have reached out to the Caregiver Support Coordinators. There are also calls once a month, and the Program uses a listserv, but it's something that can be improved upon.

Program of Comprehensive Assistance for Family Caregivers (PCAFC)

- PCAFC provides additional assistance to Veterans who were injured after 9/11. There are 22,000 Veterans currently participating and $13M a year is spent on health care claims.
- Beneficiary travel is provided, and education and training is provided to the caregivers. Most caregivers complete courses online and also have the ability to complete them in Spanish.
- Participation must be in the best clinical interest of the Veteran and support the Veteran's progress in treatment.
- Research for utilization of the PCAFC shows that:
    - If a caregiver is participating in the program, the Veteran accesses more health care. This is an example of how support to caregivers helps with providing Veteran support they need.
    - There are probably Veterans who haven't accessed services in the past that now do, so there have been increased costs.
    - Data from the Caregiver Support Line shows if someone is caring for a pre-9/11 Veteran, it's likely they have a lower disability rating. If someone is calling for a post-9/11 Veteran, there is probably a higher disability rating.
- Committee question: Is there any assessment of quality of life at the time they enter the program? And is there any follow up to see if the quality of their life has improved? If there's an increased cost, is there a way to know it's worth it?
    - Ms. Kabat responded that the challenge is looking at the caregivers themselves. VA doesn't have access to their health care utilization, so there's a reliance on self-reports. There aren't good responses from many surveys.
- PCAFC developed a "roles and responsibilities" document that clearly lays out the expectations of the Program, such as home visits and ongoing evaluations of the Veteran. The Program requires medical centers to review the document with caregivers and Veterans.
- The program found Caregiver Support Coordinators spend too much time on administrative aspects. A lot of listening was completed and rapid process improvement workshops were held to hear from staff.
- The program used the Federal Register to ask official questions to the public.
    - For the three questions asked, there were 325 responses. There are staff looking at the responses and integrating the responses with what was heard from the rapid process improvement workshops.
- Quotes from the Federal Register Notice that speak to the challenges ahead and to

	show there is not consensus across the comments include: o "The three-tier system could possibly be changed to four, so VA offices would be more inclined to tier changes and the jumping between wouldn't be so large." o "We should lose the tier system, no more appeals, and no more complaints." • Senator Dole asked: For standardizing the appeals process, can you provide the Committee with an update? o Ms. Kabat responded that the clinical appeal process came out of the Commission on Care established a couple of years ago. The recommendation to revamp the way appeals are done is coming from a few sources. These recommendations can be provided to the Committee. • The program is conducting a customer service survey that will go to caregivers and Veterans. This paperwork has been submitted with hope to get this launched over the next couple of months. • Caregivers were not mentioned in the previous VA Strategic Plan. VA just released the FY18 – FY24 plan, and it now includes Caregivers. VA understands caregivers are critical to the whole health for Veterans. • Committee question: What is the program's understanding of the impact on caregivers? o Ms. Kabat responded it varies significantly. It is known that caregivers are more likely to meet the criteria of depression. The RAISE Act will help address this. It's important that VA partners with other organizations focused on solutions for caregivers. o Dr. Davis mentioned that VEO reviewed the Strategic Plan. Also, Dr. Davis is the identified VA liaison for the RAISE Act, with an opportunity to use VEO as influence.
11:15 AM – 12:30 PM Choose Home Initiative *Dr. Thomas O'Toole*	**SUMMARY:** • The Choose Home Moonshot is about providing Veterans, families, and caregivers, the capacity and opportunity to stay at home when nursing home placement would be imminent. • There are 30,000 Veterans at imminent risk for nursing home placement in the next two years. But only half of them receive non-institutionalized care prior to nursing home placement. This ranges between facilities. • It's been found that those who receive non-institutionalized care typically have a nursing home placement that is three to five months shorter than those who do not. • The needs of caregivers and Veterans extend beyond the medical model, which needs to be embraced to be effective. • VA cannot do this alone and relies on community partners and national agencies to help the engagement with the community. • There are three lines of action (LOA) for Choose Home: o LOA 1: Focusing on the VA clinical platform and what is needed to ensure VA is effective, appropriate, and efficient in doing it right. o LOA 2: Acknowledging VA can't do it alone and how to partner effectively with community organizations to make sure Veterans receive all the care needed. o LOA 3: Establishing a Center of Excellence. Health care, in general, is shifting out of the health care setting and into the home. LOA 3 needs to inform this shift in order to do things in a smart and right way. • Dr. O'Toole provided the major milestones of the Choose Home Moonshot: o Creating a registry so that every medical center will be able to identify which Veterans are at the highest risk for nursing home placement. The model that has been developed indicates that there is an average of 200 high-risk Veterans

at each medical center. This model will be rolled out in October of this year.
    - Identifying the services that will be part of the initiative.
    - Developing metrics to hold medical centers to performance standards. This will not make nursing homes obsolete and will not make nursing homes unavailable to Veterans who prefer it or need it. It's intended to make sure services are in place to address the needs and wants of Veterans and provide a support system that allows them to stay home.
    - Identifying sustainment efforts for the initiative.
- A proposal was submitted to help determine reimbursement.
- This is viewed as Choose Home 1.0; it will be a learning process for the organization.
- Committee Question: When considering the community how does this fit into the Choose Home's definition? What are the implications of living longer with this initiative?
    - Dr. O'Toole responded that people who are living longer are in the context of chronic diseases and impairment. Choose Home's projection is that nursing home placement will be increasing, so the demand for this is huge. The 3-5-month delay to nursing home placement translates to about a $250M cost saving a year. Caregiver and Veteran well-being is the primary driver for this initiative and not the cost savings.
- Dr. O'Toole briefly reviewed the process flow map for the Choose Home Initiative. The map includes identification and assessment, bundling care, and connecting to community resources, sustainment, and accountability.
- LOA 2 is about communities and acknowledges that VA is not capable of doing this alone.
    - In the Homelessness Program, this was critical to the effort and it was operationalized to view the community for its inclusive capacities and to create structures to keep the Veteran at the center.
    - LOA 2 is in the early stages. Last week an internal meeting for VA leaders was held to kick off LOA 2. In a couple of weeks there will be another meeting with community partners.
    - This initiative has to rely on community partners and organizations that are coordinating in these communities.
- Input the Committee can provide for this initiative is greatly needed and appreciated.
- Committee question: Is there any concept of long-term care deficits in the nation or in specific communities?
    - Dr. O'Toole responded that it's known there are more challenges in rural communities.
- There are jumpstart sites/facilities for LOA 1 and LOA 2 of the initiative to learn from real experiences. Dr. O'Toole provided the specific jumpstart sites for each LOA.
- LOA 3 is focused on the Center of Excellence, but is still a work in progress.
    - Amy Kilbourne is the point person and has committed $1M in funding from her program to kick-start it.
    - There is a research group within VA Health Services Research and Development (HSR&D) to help drive this initiative.
    - There are two fellowships being supported, including one looking at the pipeline of researchers and a second looking at the caregiver environment so they become better integrated with the care team.
- Committee comment: A Vietnam Veteran with Parkinson's disease is being cared for at home. The VA hospital is 2.5 hours away and VA would not let his physician authorize a wheelchair unless he took an ambulance to the medical center to be seen in person. In addition, the Vet Centers are everywhere and there's a need to train the Centers. Lastly,

	the U.S. Department of Agriculture (USDA) can be tapped into because of their specific programs. o Dr. Davis responded that VA is communicating with USDA and thanked the Committee for bringing up the Vet Centers. o Dr. Davis reminded Dr. O'Toole that Choose Home needs to coordinate with the Whole Health initiative and needs to make sure all other relevant programs are integrated with Choose Home. o Dr. O'Toole responded that part of the planning is that every Veteran assessment includes a technology assessment. The program offices have noted that the majority of technology users are over 65, and thinks this will help in the rural communities. • Committee comment: People tend to think that older populations are not using technology. A few people think that the way things are done can't be changed because people will be left behind, but that might not be the case. • Committee question: What is needed from community partners for VA to proceed? What do the community partners need to wait for from VA? o Dr. O'Toole responded that community partner participation in guiding the effort is a dire need. o Dr. Davis responded that the three subcommittees align nicely with Choose Home's LOAs. Anything Committee members hear from the three subcommittees can be endorsed. • Committee question: There may be medical situations where it would not be wise to choose home or to counsel the caregiver to have the Veteran stay at home. Will Choose Home's work articulate the set of circumstances where choosing home would not be best? How can Choose Home infuse non- typical home services into the program? o Dr. O'Toole responded that these are important points. This initiative is, by design, being able to have the choice to stay at home over going to a nursing home. There are many instances in which staying home is not a viable choice. o It's been found that receiving non-institutionalized care didn't eliminate the need for a nursing home, but only delayed it. • Committee question: There are families and caregivers that feel isolated and other people who have been connected effectively with other partners. If VA is able to capture the whole spectrum of experiences, VA may be able to connect the isolated people using overarching strategies. o Dr. O'Toole responded that how communities are integrated is a huge part of this. Choose Home will look at the five communities that were intentionally selected for LOA 2, how they create connectedness at the community level, and how VA should partner with them. o Dr. O'Toole doesn't want to create the impression that VA will get this right the first time. Choose Home will evolve. o Dr. Davis responded that the lessons learned captured from those who do not choose home over a nursing home will be included in the LOA 3 learnings and in LOA 1. o Dr. Davis responded that the five communities chosen for LOA 2 are caregiver friendly cities and where our Community Veteran Engagement Boards (CVEBs) are. VA is going into places where there are active partners and opportunities to see what might and what might not work. • Dr. Davis commented that the Choose Home team will be meeting with community partners during a March 14th meeting. Most audience members are directly or indirectly involved in this meeting. It will include things like how to do local and national outreach to communities and how we will engage other VA offices. The intent is to provide

	community partners with a vehicle for engagement with VA.
	• Committee question: Just the way caregivers are talked to about things they've done can have an impact. Is there a way to give caregivers a voice on how they'd like to be engaged?
	  o Dr. O'Toole responded that VA is not well trained as professionals about how to partner with caregivers and how they are being supported. It comes back to how caregivers are being supported and to fundamentally rethink how VA approaches caregivers.
	  o It has to come down to fundamental skills and training, which LOA 3 will help address. There is a deficit right now and it will not be an easy fix, but it has to happen as a caregiving system and a learning organization.
	  o Dr. Davis responded that VA is the largest educator of health care professionals in the country. If VA gets it right, VA will be changing the culture and influencing the health care system in the country. There are opportunities including:
	  ▪ PX experience training
	  ▪ USAA training for educating providers; VA has a couple of offices endorsing this program
	  o Dr. Davis responded that this Committee has an opportunity to provide feedback and recommendations.
	• Committee comment: VA does have a grant process for construction of nursing homes. The Committee is glad the focus is all-encompassing for choosing home or going into a nursing home.
	  o Dr. O'Toole responded that one of the services provided at state nursing homes is Adult Day Care services and thinks it's an area that needs to grow.

12:30 PM – 1:30 PM Lunch	

1:30 PM – 1:40 PM
Domestic Violence
 	
Meg Kabat
	SUMMARY:
	• The Domestic Violence Program was initiated in 2013 under Secretary Shinseki after a meeting with DoD to learn what DoD is doing about domestic violence.
	• The program includes 14 recommendations to implement a comprehensive program and screenings.
	• There are specific areas of action:
	  o Raising awareness and training
	  o Community partnerships: there is a Memorandum of Understanding (MOU) with the domestic partnership hotline
	  o Screening: Asking questions like "should every Veteran be screened?" or "Should every female Veteran be screened?"
	  o Partnering with other VA programs
	• The program has a good relationship with Healing Household 6, which is an organization dedicated to domestic violence in the Veteran caregiver population.
	• The program has also had great conversations with the Caregiver Support Line.
	• Leanne Bruce is in charge of the Intimate Partner Violence Program.
	• Committee question: When someone comes in for a check-up, are there questions about this?
	  o Ms. Kabat responded that the Women's Health Program has specific questions and VA is looking into expanding the questions to all Veterans.
	• The program partners at the local level to ensure that staff know what to do. There used to be a lot of anxiety when asking people if there is violence in their relationships and what to do if someone says "yes".

	• There are six sites that uses an evidence-based program and VA is hoping to expand it. This program is a mandate without funding behind it. It's a grassroots effort and the program is working with a lot of people who are passionate about the issue.
	• Committee comment: Healing Household 6 is one of the only organization helping with this issue and has a healing recovering model. They have been really successful.
	• Committee comment: This is a big issue in the survivor community.
	• Committee question: How is the stipend being expanded to situations with violence?
	  o Ms. Kabat responded that the dilemma for VA with continuing the stipend is that VA needs to be doing something within the home. It's a complicated issue; many times, VA has heard a Veteran doesn't want a caregiver to be their caregiver anymore, and then they reconcile a few weeks later. There are other complications related to child violence.
	• Committee question: Is there any collaboration with the "me too" movement?
	  o Ms. Kabat responded that there's nothing right now to collaborate with in regard to the "me too" movement. The movement appears to focus more on sexual assault.
	• Committee question: Can VA provide more guidance on how the Committee can help screen for this issue?
	  o Ms. Kabat responded, "Absolutely."
	• Committee comment: People don't want to lose the importance of what they are trying to address by clinging onto something that is "glamorous" (referring to the "me too" movement). "Domestic violence" is the term that the general public is familiar with; use that to grab people's attention but then get into more specifics.
	• Committee question: Is there a relationship between this program and the Crisis Line?
	  o Ms. Kabat responded that she needs to check with Leanne Bruce.

1:40 PM – 2:10 PM
VBA/ Benefits Assistance Service – TAP briefing
 	
Margarita Devlin
	SUMMARY:
	• Ms. Devlin provided an overview of what the Benefits Assistance Program and TAP are doing.
	• TAP refers to an interagency effort between DoD, Department of Labor (DoL), Department of Education (DoE), Homeland Security, Office of Personnel Management (OPM) and VA through a MOU.
	• Part of TAP is a VA curriculum, which is a six-hour program with two sub-programs. The two sub-programs include:
	  o Benefits Veterans can apply for
	  o Health care services
	• There's a new curriculum rolling out on April 2nd that speaks to some of the feedback received on the program.
	• Service Members and Veterans can take the class as many times as they want, but they must take it within 90 days of pre-separation.
	• The course evaluation scores are very high; TAP doesn't receive anything under 94 percent. The evaluation asks questions about the presenters and the materials. There is also a place for narrative comments, which are reviewed every quarter.
	  o For example, feedback received includes having a separate course for the Guard and Reserves.
	  o In response to this feedback, the program now offers a separate program for the Guard and Reserves.
	• The new curriculum is more personalized. TAP created a workbook that contains guided exercises to challenge participants to think about their own personal journey through modules including:
	  o Identifying goals

	○ Supporting yourself ○ Getting career ready ○ Finding a place to live ○ Maintaining your health, including whole health ○ Staying connected to VA resources and other community groups • The Secretary asked TAP to facilitate registration. Now, if someone is 180 days from pre-discharge they can put in a later date so VA can adjudicate their health care. • TAP is working with target populations including Homelessness and Suicide. For example, there is a pilot program for taking female Veterans into a separate classroom to learn about female related programs and allow them to tour certain sites. • TAP is also looking at emotional wellness factors including social connectedness. How can this be incorporated into DoD and other huge agencies in a way that will work? • Committee question: Are there special programs for minority challenges? ○ Ms. Devlin responded that there are specific programs within VA but not specifically within TAP. TAP does tell minority Veterans about the Center for Minority Veterans. • TAP is open to spouses and families. For example, spouses can make an appointment to speak with advisor one-on-one. Ms. Devlin learned that they don't always know it's available to them. • TAP has created social media platforms to connect with families. Ms. Devlin asked the Committee to provide examples of other platforms that could be used, as marketing the Program has been challenging. • Committee question: is there a specific platform for caregivers? ○ Ms. Devlin responded that TAP is the same for everybody. However, TAP will send a benefits advisor to a hospital room if someone can't make it to the classroom. The caregiver can be present for that. • Committee comment: VA doesn't often facilitate access to TAP. ○ Ms. Devlin responded that TAP has an electronic module on Joint Knowledge Online (JKO) and is in conversations to get the program on certain platforms. TAP needs to do a better job of this coordination with DoD. ○ Benefits Assistance Services is working on military lifecycle modules that will be in addition to TAP. Whether or not someone is staying in the military or has residual issues at the moment, all disability programs will be covered. • Committee comment: There is a lot of information at the end of five days. Younger Veterans are asking for different ways to access information. Also, younger Veterans do not identify themselves as Veterans, which may have impacts on getting people to access certain benefits. ○ Ms. Devlin responded that she thinks about this as her son is currently a Marine. If someone is retiring from the military they get a ceremony. But if someone leaves at the end of their contract they don't get one. Wouldn't it be awesome if a ceremony was held for everybody? This is potentially something that can be done at VA with either a certificate or a ceremony. • As people go through this program they don't know what they don't know. TAP put together a video that has Veterans explaining to people in the program what they wish they had known. • The family piece is a challenge. Even though DoD has specific programs, the families often aren't aware of TAP. • Committee question: How is the Guard and Reserves reached? ○ Ms. Devlin responded that they go through the same program minus the specific Veteran benefits pieces they don't qualify for.

	• Committee comment: We've heard that the families don't receive financial assistance to attend the Program.
	  o Ms. Devlin responded that JKO is a solution and has heard it's interactive. Another solution, which might not work for everyone, is sending the family to the closest installation.
	• Committee comment: It's been brought to the Committee's attention that since 9/11 there are codes being used to save money and keep families from accessing benefits. This Committee and VA attendees here can help shine light on this issue.
	  o Committee recommendation: Secretary of VA and Secretary of Defense should work together to address this issue.
	  o Committee recommendation: Loop in the employers of Reservists. What it means to operationalize the Reserves can be addressed by this audience.

2:10 PM – 3:10 PM
Subcommittee Report Outs
 	
Gaps in Innovation subcommittee: Jamie Hart
 	
Access and Eligibility: Bonnie Carroll and Melissa Comeau
 	
Education and Awareness subcommittee: Mary Keller and *Francisco Urena*
	SUMMARY:
	Gaps in Innovation subcommittee: Dr. Jamie Hart
	• This subcommittee recognizes that good policy emanates from evidence-based research. Focusing on the research will show what to prioritize and what's known and unknown.
	• The subcommittee commissioned Atlas Research to do a comprehensive literature review to:
	  o Identify and summarize gaps in services, information, and education
	  o Identify gaps in knowledge for people providing services to populations
	  o Provide a synthesis analysis of what is known and unknown
	• Dr. Hart provided an overview of the literature review methodology including the databases, search parameters, and exclusion criteria.
	• The search came up with 13,248 hits, and about 2,400 were explored and put into a citation software. Ultimately, about 300 full text articles were downloaded and reviewed.
	• To address gaps in direct services, Atlas Research found that Veterans, caregivers, and families may not be accessing support, and the subcommittee wanted to know why.
	  o Caregivers may not be adequately supported in the direct services made available to them through VA.
	  o Veteran family members need to be able to identify what supports are available and most suitable to needs.
	  o Additionally, which is not on the slides, Atlas Research looked outside of the online social support services.
	• To address gaps in policy, Atlas Research found:
	  o There is a lack of policy that supports the expansion of coordinated health care within rural areas. A strategy for consideration is public/private partnerships.
	  o Caregivers require support through the expansion of programs providing financial assistance to offset income loss.
	  o Current education policies do not identify Veteran children within school systems as they do for active duty military children.
	• The literature also addressed the following:
	  o The importance of seeking help and that it's okay to seek it. Also, it pointed to resources for individuals dealing with stress.
	  o Home health clinicians
	  o Civilian providers could benefit from training in military culture
	• There are gaps in education, training, and knowledge. Two key groups Atlas Research identified include:
	  o School staff who can connect to Veteran children

- Health care and community providers
- Gaps in research include:
  - The need for more longitudinal data
  - Gaps in population including parents of Veteran children, children with the impacts of non-visible issues, caregivers of Veterans with traumatic brain injuries (TBIs), children of Veterans in general, and survivors
  - The differences between the sub-populations and their basic demographics
  - Pairing satisfaction with whether or not care is effective
  - Societal cost savings provided by caregivers
  - How to protect caregivers and recipients from harm
  - Understanding influencing factors and variant trajectories in the reintegration process
  - Understanding the survivor experience
- A RAND report study looks at how programs can be more accessible.
- Committee comment: We really appreciate what Atlas Research has completed. Committee members may look at this and ask why it was completed. It can be reverse engineered. If there are recommendations based on expertise, the dots can be connected to this report on the evidence-based research. The other subcommittees want to look at this report to understand what needs to be done and how to prioritize the gaps. It can also be used as a roadmap for further research.
  - Dr. Hart responded that everything in this report includes a footnote and it will be provided to the Committee electronically.
  - Dr. Davis responded this report is neither final nor ready for distribution.
- Dr. Davis commented that because the way parameters were set (e.g., excluding pre-2014 data and disregarding purely Veteran references) some important information may have been omitted. For example, there is a whole center dedicated to TBI research.
- Committee comment: In the recommendations of the report, consider asking the Secretary of VA to work with other government agency Secretaries.

Access and Eligibility subcommittee: Bonnie Carroll/Melissa Comeau

- Ms. Carroll commented that the challenge for this subcommittee is determining the current state and challenges. A question the subcommittee has is, "How can the subcommittee have the greatest impact during the timeframe provided?"
- The subcommittee was interested in receiving comprehensive data on feedback and complaint data on specific populations to identify trends and incorporate the voice of the Veteran. As part of this process, the subcommittee:
  - Tracked the relevant calls to the White House hotline
  - Looked at mailed and online surveys to provide insights, and talked to Blue Star Families about the surveys they deploy
  - Identified the need to understand what other VA advisory committees are doing
- The subcommittee found that caregivers are exhausted from dealing with a loved one suffering with PTSD. The subcommittee would like to address this gap in access and eligibility.
- Ms. Comeau commented that the subcommittee members heard feedback that people didn't always understand the Federal Register questionnaire.
- Major themes from the subcommittee's activities include the need for:
  - Consistency in eligibility determination: It is not consistent across facilities, and the tier system is hard to understand
  - Effective clinical appeals process: There is inconsistency in how appeals work based on location and tier levels, and the process isn't well communicated

- Consistency in payment and looking at a single payment rate
- Need for a permanent status for caregivers and Veterans
- Need for change in payment adjustment period
- Need for a "failure in participation" indicator to raise a red flag for reassessment
- Need for checking in with Veterans and caregivers

- Committee comment: There are times when people hear from caregivers that the person they are caring for is getting better. This doesn't mean there's another job for the caregiver to go to that day.
  - Ms. Comeau responded that she recommends caregivers be given a period of 90 days to deal with reduction in income.
- Committee question: What triggers reassessment?
  - Ms. Comeau responded there's an annual reassessment.
- Committee question: Is Ms. Comeau only talking about the stipend program?
  - Ms. Comeau responded "yes".
- Dr. Davis commented that to make changes, the Committee needs to be mindful that VA needs the authority to make those changes.

Education and Awareness subcommittee: Dr. Mary Keller/Francisco Urena

- Dr. Keller commented that when the subcommittee first met there was talk about expertise each member brings to the conversation.
- Overall themes included:
  - Increase awareness of benefits and services
  - Roles of caregivers
  - Public outreach
  - Stigmas
- Mr. Urena presented on the meetings and briefings to date.
- The committee developed a rubric construct incorporating VA's, "Moments that Matter" and the journey maps.
- Problem statement: Recognize there is a paucity of actionable information/reliable and comprehensive data about the varied experiences of Veterans, families, caregivers, and survivors as VA users/customers.
- Dr. Keller presented a slide that included opportunities, objectives/target state, benefits, and measurements to consider.
- Dr. Keller's requests of VA include:
  - What data already exists inside VA?
  - Would VA please identify and consider a user experience audit and consider the rubric construct as a framework?
  - How can the data be connected to knowledge and to practice?
- Dr. Davis commented that she likes the distinction between the user and Veteran experience. She invited the subcommittee to attend a briefing on VEO's efforts to help make sure the subcommittee isn't just focused on the health care experience.
- Committee question: Has anyone done a measurement of providers?
  - Dr. Keller responded the physician survey is part of the recommendation.
- Committee comment: It seems there needs to be another advisory committee on the public/private partnerships and the impacts. The lessons learned, value, contributions, and impact they have seem immeasurable.
  - Committee responded that the subcommittees need to be sure to make recommendations not addressed specifically to government agencies.
  - Committee responded that the "public/private partnership" term has nothing

	to do with non-profits, which is how it's usually thought of. This became a barrier. ▪ Dr. Davis responded that in VA's MOUs the "public/private partnership" term is not used and instead says things like "collaboration." Because VA can't endorse or task other organizations, the Secretary actively uses terms like "guide star" to refer to other partners. • Committee comment: A partnership is a mutually, legally binding agreement. If an entity enters into a partnership, the other party has the same liability. Because of this, it's best to develop statements of collaboration agreements. If the overall goal is to improve care to caregivers and survivors, it doesn't help to get stuck in silos and in jargon.
3:10 PM – 3:30 PM Break	
3:30 PM – 3:45 PM University of California, Los Angeles (UCLA) Family Wellness Center *Tess Banko* *Patricia Lester*	**SUMMARY:** • Ms. Banko commented that UCLA's Resilience Center promotes resilience and enhances care in military and Veteran families. Competencies include: o Translation service o Family centered services and care o Provider and community training o Innovative technology • Veterans and their families live within an interlocking system. UCLA wants to work with each person in the system for a whole family approach. However, there are several things standing in the way of family centric care. • The FOCUS (family overcoming under stress) model is an evidence-based practice shown to be effective in a number of trials; UCLA has adapted it to the Marines. Out of this experience, UCLA continued to listen to what families need. From this, a suite of services has been developed. • FOCUS is an educational and prevention model that serves as a portal for Veterans to receive resilience services with their families. The model includes core family training that can be taken in person or on the web, provider consultations, and large educational workshops. It is a skill building model. • UCLA also helps families share narratives and make sense of what they experienced during transition. • The goal is to have the families be leaders of their own systems, understand each other, and foster closeness. At the end of the program, there may be several identified needs. • This is data driven; everyone gets screened on mental health as they enter into the program. This is a prevention program and UCLA is able to see how people are doing after they go through it. The program has found that there are areas of reductions by half of levels of symptoms of anxiety and depression. Ms. Banko presented data to show that reduction of symptoms stays steady over time. • The program has faced challenges with the fragmented situation in terms of all the different players in the LA landscape, and it was hard to figure out a way to bring families to VA. UCLA started to listen to Veterans groups, and it became clear that there's a gap for Veterans families on the campus. o A model is needed that could bring in pieces of the campus' capabilities. o There are several organizations that want to help and connect Veteran families with the Veteran Family Wellness Center. • Committee question: There is so much discussion in the nation about resilience and wellness, is there work indicating "now you are resilient"? How is a standard

	established to say someone has what they need to be resilient? o Ms. Lester responded that a constellation of metrics can be considered, as well as mental health metrics. Resilience is challenging because it only occurs in context; there has to be a stressor. UCLA has focused on building those kinds of skills and capacities that are known to be helpful. • Ms. Lester is the Director of the Wellness Center. Getting back to the systems of support, Ms. Lester commented that she's honored to be part of the Veteran Family Wellness Center. • Ms. Lester spent three years on active duty in the Marines, was sexually assaulted, and was injured, which ended her military career. She went through a rough transition point, and was married to a service member that died of suicide. The casualty officer told her to go to school, and she went into social work. She remarried a man who decided he wanted to become a military officer and she was left home with a one year old and was diagnosed with PTSD. • The program officially opened doors in August and was located in building 220 of the West LA Campus. The program is one of the only programs on the campus that serve Guard and Reserves. • The Wellness Program's approach to engage families is through a continuum of services including skills building groups, parenting classes, tele-wellness, caregiver support, women's veterans programs (REAL), and grief and loss. • The program operates across wellness domains, known as pillars. Under the pillars there are sub-populations. • The program has one central coordinator that takes calls, emails, and walk-ins. • The program has found that it acts as an additional layer to VA services. Veterans often come to the program for immediate consultation for benefits. • Challenges include integrating with VA systems and opportunities include partnerships and connection to the campus. The program wants to be able to integrate into VA's whole health model.
3:45 PM – 4:00 PM University of Southern California (USC) Veterans Collaborative – Families and Children Subcommittee *Lauren Trosclair Duncan*	**SUMMARY:** • Ms. Duncan commented that she's fortunate to have worked with the Red Cross and go to USC and partner with women Veterans to find out what they need. She is mindful that she does not stand in their shoes, as she's not a Veteran and is forever an outsider. She can recognize challenges they have and let them know she's here for them. • Women Veterans are often the last to ask for help. They are a group of people not to be pitied, but we should be watching for what they need. • Ms. Duncan commented that she wants to educate women Veterans on what's available to them and what to do. More than anything, it's a sisterhood Ms. Duncan hasn't felt on any other level. • Ms. Duncan's colleague, Felicia, is a 23-year Army Veteran and a military brat whose dad did three tours in Vietnam. PTSD took a toll on Felicia's dad and he died of suicide. • Felicia works with the Army and USC. On a daily basis, she receives phone calls from families and soldiers and works with active Reservists. Her job is to contact resources that help Veterans and their families. • Felicia identified two primary areas of concern: o Children who are the "silent survivors." The impact children go through is unimaginable. Callers want VA to implement a program to assist the children. o Issues with the Department of Housing and Urban Development (HUD) VASH program. Families say it appears to be too long and there's a stigma that it's located in mental health. USC now has programs being implemented with city

	council members to provide more funding for housing.
4:15 PM – 5:15 PM Public Comment	**TRANSCRIPT:** Jenny Chen-Hansen • I am vice chair of another FAC. We've talked today about how we can collaborate with each other. Our FAC focuses on Veterans themselves and those who provide professional care. We do that by our opportunity to work with 20 centers throughout the country. • My core focus is on the older Veteran population. With some of the research work that has been done, an appropriate strong focus is on the post-9/11 population. • It was interesting to hear about some of the research and the literature review. I would offer that within these 20 centers of our work, that we produce an annual report that goes to SECVA, the Under Secretary of Health, and Congress. • Every year we have recommendations. There are some core areas within VA that are not easily addressed, including the fact that half of the people who use VHA services are over 65. There needs to be focus on how best to serve people with the complexity that comes about in aging and physical and cognitive issues. • Our focus is on the people who would like to stay at home. Our emphasis is how to prepare individuals with the ability to understand older Veterans. • Our committee was formed in 1980. We would love for our piece to complement your work. As a collaboration point, we have a professional workforce with competencies in many areas. • I was involved with helping to set up a program, for 25 years, to help older people going into nursing homes to stay at home. This program was called PACE. It's now Medicaid law. • My last full-time position was the CEO of American Geriatric Society. • My father was a World War II Veteran and my brother served in the Korean War. I think we are all tied in some way or another. Dr. Gregory Leskin • I would like thank Senator Elizabeth Dole for her tireless efforts to support Veterans, caregivers, and survivors. I would like to thank the support of VEO for having this committee in southern California. • Southern California is home to biggest population of homeless Veterans. • I'm a licensed clinical psychologist, born and raised here. For the past 25 years, I worked on implementing programs to address behavioral health needs of Veterans. I started here as a psychiatric clinician providing treatment to Vietnam Veterans with PTSD. • We appreciate the nature of the risk to Veterans, Service Members, and families. Many Veterans suffer from mental health issues like depression, panic, and anxiety; they have thoughts of suicide behavior as a solution for their ills. Many suffer from physical scars and ails of war exposure. • The families of these Veterans experience negative "after effects". They may experience parental instability, which can lead to divorce and estrangement. The rate of divorce may triple after transition to civilian life. Military families may experience multiple and sudden transitions. However, the transition to civilian life may be most critical. • For some, this may be a welcomed change for greater permanence. For others, leaving service may be marked by loss of support systems. A smaller percent may experience secondary PTSD from homelessness, substance abuse, the experience of being bullied, etc. • I have the opportunity to work with communities and practitioners to help with successful transition. Our program provides workforce training to behavioral health

staff with cultural aspects. We adapt evidence-based treatments to improve the lives of families to be relevant to specific needs of Veterans.
- We stand ready to aid in the needs of families, Veterans, and caregivers and to review the recommendations of this advisory board.

Howard Hernandez: American GI forum
- I am a Vietnam combat Veteran and returned in 1972. After years of transition, I attended law school.
- I'm a native to southern California and proud to say California has the greatest number of Veterans. You are sitting in LA County with the largest number of Veterans in any county in the United States. With that being said, thank you for your attendance today.
- I would like to say I'm a chartered member of the LA region community and Veteran engagement board. I was part of the advisory panel during the appeal of the building across the street.
- I'm a member of the Green Lining Institute, which focuses on low income and middle income and getting a Return on Investment (ROI) from bankers and insurers—making sure that these interests are returned to our communities.
- One of the things that came up last Thursday is that of the 20 suicides per day, six have ties to VA. This means the 14 other Veterans don't have any connection to VA. This leads me to believe that there is a serious deficiency in meeting the needs of all these Veterans. This is a very serious lack of production.
- I'm very glad to see that finally the property across the street will be transitioned for Veteran centric services, including legal, clinical, and the Veteran Resource Center.
- I would like to offer any of our services. I'm at your service, LA is my home.

Stephanie Celvin-Howard: Weight of Honor
- I don't have any prepared notes because I didn't expect to speak; I was asked to speak.
- I know several of you in the room; several were interviewed for the film Weight of Honor. Meg is in the film.
- The film is about caregivers. I come from a civilian background; I didn't know this population exists to the extent that it does.
- I came here to seek what is new in the caregiver space. I see what you are working toward and I'm honored to know you and what you're working for.
- Six years ago, no one had done a documentary about military caregivers. I took longer than I expected to produce this film because I couldn't leave them at a certain point and I had to follow their stories. These people invited us into their homes and said very intimate and private things. They wanted the rest of the audience to know what they are going through and what assistance they need. These are resilient people. They are brave people.
- The problem is, six years later this is still the only documentary on military caregivers. No network wanted to put it on air including Netflix, Own, Lifetime, etc. They weren't interested. One reason is because they were tired about hearing about the war or asked, "There is still a war going on?"
- I'm asking for help in shaking up the civilian population. When people ask me what they can do, if they are a non-profit organization, I tell them to identify some families in your community that you can help directly. Help with the little things. Help with watching the kids. Help with mowing the lawn.
- I need for all of you here to help get the word out. They are as much of the population of America as everyone else.
- Committee comment: There is no ending to that struggle.

- Make a commitment and continue with that commitment. If you are helping someone with cancer, you aren't going to drop the ball and stop providing support.

Joel Connor

- I introduced myself to Dr. Davis, who encouraged me to talk to these people so we know about the caregiver part of this system, which is professional fiduciary.
- I'm a professional pharmacist, and went to law school. I also am a fiduciary.
- I'm the financial advisor for 36 Veterans. Often these Veterans' families have died or their families don't live near them.
- When I get appointed, almost always they wanted me to get a conservatorship. There was a very hard turn and we weren't allowed to say the term "conservator." As a fiduciary and a payee, we had no authority other than to write checks.
- My Veterans can't make medical decisions and they can't manage finances. As a payee I can't do anything for them. If they spend their allowance in the first two days in the month, they call me every day saying they need more money. Then they start calling the hubs and the hubs start calling me.
- The VA needs to consider these professional fiduciaries who are trying to care for these people; we need the support of VA. VA needs to stop and think if you're looking out for the best interests of Veterans when they refuse us to seek conservatorships. In California, it's about $15,000 to get the whole thing set up. Make sure they are being cared for through the end of their lives.

Stan White

- Thank you for allowing me to speak; I've learned a lot today.
- I would like for this committee to look at the effects that psychotic drugs have on Veterans and caregivers.
- Explore CPLchadO.org. Chad died from medications.
- Between 2005 and 2011, there was a 22% increase in psychotic drugs. In the active duty military, it was a 20% increase.
- There are many helpful groups out there. A lady called me that started a program in Florida called Live to Tell organization. All these programs have the hope to get you to recovery, but what's effective is that you come away with comradery and people to reduce the drugs.
- Put a database up that every Veteran and caregiver has access to.
- Dr. Davis commented that Shirley and Stan's son is mentioned in a book and speaks to the opioid epidemic.

Ms. Kyle Orleman

- Thank you for the welcome. I've been living this life for a long time; I'm going to give you a short version. You are the people I've been wanting to talk to.
- I was an only child growing up in Chicago.
- I met my best friend, who spent 3 years in the jungle, and I was beginning to learn about Vietnam. I don't know his story because he won't talk about it. He's fine. He gave me books that told me about what he'd been doing and started teaching me terminology.
- I met some gentlemen during a workshop and we were taught a specific type of communication. I have the advantage of being able to communicate what most people have to learn through therapy.
- I was in a bad accident. A good friend ended up being my caregiver and we got married. A week after we met we had our first date and 18 months later I fell in love with him.

	• His health was so bad at the time we married because of Agent Orange exposure. I thought if we made it to our 5th anniversary that would be a miracle. We will have our 25th in July. • He's rated by VA as 100% disabled. He had a triple bypass here, but had ischemic heart disease, not considered service connected, so he was turned down for $100,000 in insurance coverage. • I couldn't leave the house (because of caregiver duties). I started connecting with people on Facebook because I couldn't leave the house. They are spread all over the country. I got online in 2008. I couldn't leave the room because he was so suicidal; those were my only contacts. Only two of us are not yet widows. • In California, 83 percent of most severely disabled veterans are pre-9/11. None of us have access to the Caregiver Program. I have nothing but respect and admiration for the post-9/11 families. Many are widows, have raised their own children, and put aside their careers. • For pre-9/11, the Gulf War Veterans are invisible. Vietnam Veterans are dying. A woman has a husband and 30 days later is having a funeral. • My husband is having surgery next week and that could be his moment. • My city has many people who are rocket scientists, Veterans, etc. I go to local meetings to push for the Caregiver Act. My city council passed resolution after resolution to pass legislation to expand the Caregiver Act. • I was cited by code enforcement for $1,000 per day because weeds grew so long. Do you want me pulling weeds or keeping him alive every day? At 4 a.m. when he has GI issues and can't make it to the bathroom, that means I have to clean him up like a toddler; what does that do to a man who served his country for years? • By the way, I'm wife number three. The others didn't do anything. It is the practical things, like getting someone who can clear the weeds, since we don't have the Caregiver Program and we are living on Social Security and his stipend. • On the day that I lose my prince, I will be homeless within 30 days. That's what happens to us because we do everything that we can but when we are in our 60s we are lifting them out of the bed, doing the toileting, doing everything to keep their dignity intact. • When we go to these different agencies what we get over and over is, we only help post-9/11. We could have been the peer support and mentors; we don't have the opportunity because the online stuff got so ugly. We are not the Hidden Heroes, we are the buried population. We have to do everything we have to do so people can die in their beds with their own families. Money will fix it, but we don't have it. Find a way to get the financial help we need.

Friday, March 2, 2018

9:05 AM – 9:05 AM Call to Order *Hon. Elizabeth Dole*	**SUMMARY:** • Senator welcomed the committee • Ms. O'Shea provided an overview of the agenda for the day, including the facility and grounds tour.

9:05 AM – 10:15 AM
Facility and Grounds Tour
	LOGISTICS:
	• Fisher House
	  o POC: Erma Mickens
	  o Driver: Voluntary Service
	• Family Wellness Center
	  o POC: Tess Banko, UCLA/Lisa Altman, GLA

	○ Driver: Comms • Welcome Center ○ POC: Heidi Marston ○ Driver: TBD
10:15 AM – 10:30 AM Break	
10:30 AM – 12:00 PM Listening Sessions *Facilitators:* *Steve Schwab* *Carolyn Alchowiak* *Jamie Hart*	**Please see 1:00 PM – 2:10 PM report out from listening sessions**
12:00 PM – 1:00 PM Lunch	
1:00 PM – 2:10 PM Report back from listening sessions/sharing insights *Hon Elizabeth Dole* *Steve Schwab* *Carolyn Alchowiak* *Jamie Hart*	**SUMMARY:** **Caregiver Listening Session: Steve Schwab** • Participants: Local and non-local Caregivers; Pre- and post-9/11 Caregivers • Systemic Challenges ○ Inconsistency in execution of programs ▪ Strategy: Prioritize at Veterans Integrated Service Network (VISN) level; give National Office authority to weigh in and ensure requirements are being followed ○ Lack of cultural competency (e.g., with Caregivers themselves and with staff about role of Caregivers; lack of diversity) ▪ Strategy: Training for staff on cultural competency ○ VA's assumption of fraud sets up an immediate confrontational relationship ○ General fear and anxiety around the Comprehensive Support Program, especially home visits ▪ Strategy: Consider some virtual visits; Clarify expectations of Caregivers ahead of time ○ Pre-9/11 Caregivers do not benefit from all services and supports ○ Most providers provide great care so the experience with doctors is positive, but: ▪ Not all providers are trained in establishing relationships with Caregivers and some are not desirous of establishing such relationships, therefore Caregivers are not systematically integrated ▪ Providers do not always document scenarios presented by Caregivers in the medical record ○ There is a lack of urgency on treatment follow-up within the VA system ○ General bias against mental/emotional/stress-based disorders ▪ Have to make a case for importance relative to primary health disorders ▪ Lack of competency around these disorders ○ Impact of a flippant comment and how lasting that can be (e.g., related to suicidal tendencies) • Caregiver Needs ○ Systemic training on who Caregivers are, why they are important, and how to integrate them ▪ Research how they are currently being integrated

- Respite needs
  - Challenge is that VA cannot provide for childcare
  - Lack of benefits for pre-9/11 Caregivers
- Training for Caregivers on how to provide CPR at home (e.g., related to seizures)
- Caregivers are given little or no notice for visits that will determine status (nuance between "check in" and "check on")
  - Strategy: Schedule visits much further out with clearly identified objectives
- Expand programs (e.g., mileage, ride share)
- Alternative treatments (e.g., acupuncture, medical marijuana)
- Proper handoff to a new or evaluating nurse
- Need for linking up Caregivers (both those in and those not in the program) with other Caregivers for support and information
  - Strategy: Provide access to existing publications/newsletters for Caregivers; Develop a VA-led publication (e.g., Veteran of the Day)
- Education on community resources for Caregivers to support VA services
- Create community of Veteran peers
- Provide respite opportunities for entire families
- More focus on empathy from VA counterparts and more reinforcement to ensure effective transition
  - Strategy: Contact upon discharge; Adjust medical terminology in discharge papers

Families and Survivors Listening Session: Carolyn Alchowiak

- Participants: Survivors, Veterans, Caregivers, educators and supporters for these populations
- Key Challenges and Solutions
  - Lack of cultural competency related to medical and military terms
    - It is like walking into a new world for Veterans and Caregivers
    - Lack of recognition by VA staff that Caregivers do not always understand the terms and things they need to do
  - Lack of understanding as to why things are the way they are
    - For example, if doctor is aware of the need for a higher disability rating, why did the Veteran and Caregiver need to pursue this themselves?
  - Lack of accountability from VA staff
    - For example, length of time to correct indiscretion
    - For example, length of time for follow through after an assessment
  - Lack of leadership from VA
    - For example, lack of truthfulness and transparency when discussing issues with Veterans and Caregivers
  - Lack of confidence that VA staff are in the correct role, can do the job correctly, and know the appropriate resources
  - Survivor challenges
    - Lack of consistency and connectivity across Department of Defense (DoD) and VA—bureaucracy stops the services
    - Strategy: When transitioning, have VA opt out instead of VA opt in option
  - Lack of self-identification, but awareness of efforts nationally to help this happen
  - Gaps in knowledge of VA as an organization and how the system works (e.g.,

learning curve)
    - Nobody knows how the organization is set up, including VA employees
    - Drop off of support for Veterans over time
    - Perspective of some in group that current VA administration was improving things
        - Centralization is important vs. discretion being given to VISNs, which undermines implementation of best practices and decreases accountability
        - Creation of a platform for best practices across the system—but will they be implemented?
            - Questioned why VISNs (barriers to good ideas?)
        - Previous division between policy and operations was a barrier but this has improved
    - Holistic approach to health should be supported
    - Common theme: Ensuring no one has to go through the same experience that they did
    - Sense of a lack of consistency
    - Need for greater support for older and aging Veterans
    - Lack of understanding as to why some received some benefits and others did not
        - Strategy: Provide information about how/when qualifying for something would be beneficial
    - Need for a better approach to the services provided for death or suicide

For Committee:
    - Need to do more to understand the survivor experience and available benefits
    - Push for interoperability would help address many of the gaps (present to Shulkin)
    - Look at what should be stopped so services can be reallocated

VA Staff Listening Session: Jamie Hart
Participants: VA Facility Staff
Themes for VA Facility Staff

- Inconsistency—especially need for standardized appeals process
- Need for more effective communication modalities—in person, then online, then paper
- Need for age-appropriate services (e.g., 80+, "mediatric" population, post-9/11)
    - Emerging wound-illness-injury profiles means a generation of Veterans with a mixture of brain-related and mental health conditions
- Transportation and access challenges (e.g., cannot afford to stay overnight)
    - Agreement that telehealth is underutilized
- Domestic violence experienced by Caregivers
    - Need to consider the 90-day bridge when Caregivers and Veterans separate
- Incomplete continuum of care facilities (e.g., VA does not have assisted living facilities)
    - Lack of awareness of the new VA Strategic Plan (e.g., assumption that housing would be for homeless Veterans)
- Preparation for OEF/OIF Service Members, Veterans, and families— How will VA address the projection for an increased need for nursing home care?
- Lack of internet or wireless access
- Acute health care is prioritized vs. long-term care
- Lack of tracking on survivor experiences
- Challenge/Objective: Simplify and streamline Information dissemination

- Strategies:
  - Translate into plain language
  - Offer range of options: written, online, in person
- Challenge/Objective: Standardize the appeals process
  - Strategy: Standardize the appeals process
- Challenge/Objective: Provide training for providers
  - Strategies:
    - Encourage them to engage with and translate information for Caregivers/Families/Survivors and Veterans
    - Be aware of and address stressors
- Challenge/Objective: Provide support for non-institutional care
  - Strategies:
    - Maintain connectedness while at home (e.g., through team visits)
    - Provide adult day care programs
- Challenge/Objective: Strengthen Caregiver/Veteran relationships
  - Strategies:
    - Provide training and support on Intimate Partner Violence (IPV), financial issues, building relationships, etc.
    - Extend the 90-day period when Veterans and Caregivers separate
- Challenge/Objective: Address transportation challenges
  - Strategies:
    - Outsource care to local providers (e.g., nursing homes)
    - Expand use of telehealth
    - Ask VA to pay for support through assisted living facilities
- Challenge/Objective: Address generational challenges through age-appropriate care
  - Strategies:
    - Proactively address the changing population
    - Increase and combine online engagement opportunities with face-to-face options
- What would you change?
  - Caregivers need to be paid to help relieve economic stress
  - Conduct more research on Caregiver stress and train VA support personnel
  - Change policies about housing and travel (e.g., offer Veterans the same travel per diem as employees)
  - Provide opportunities onsite for:
    - Engagement of family members (e.g., space for children in waiting rooms)
    - Discussions between resource providers and Veterans and Caregivers (e.g., peer groups)
  - Provide more education for:
    - Staff:
      - So they recognize the role and value of Caregivers
      - Working with survivors (e.g., saying “died by suicide”)
    - Caregivers: So they are aware of all resources
  - Increase:
    - The number of staff overall that support Caregivers, families, and survivors (including chaplains)
    - Support for existing programs (including the Comprehensive Assistance Program)
    - Consistency through the systems when cases transfer

	For the Committee: ○ Focus on simple changes that can happen now ○ Explore partnerships we can form with other departments (e.g., IHS)
2:30 PM – 2:40 PM Recap, Subcommittee Charge, Adjourn *Gaps in Innovation subcommittee: Jamie Hart* *Hon. Elizabeth Dole*	**SUMMARY:** • The subcommittee groups will now meet with each other • The next Committee meeting will be held in September • Thank you for attending • Meeting adjourned
2:40 PM – 5:00PM Subcommittee Working Groups	**SUMMARY:** • Each subcommittee met separately to develop a new plan of action based on the meeting proceedings

Christine M. Merna
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Approved

Christine M. Merna, DFO

Elizabeth Dole
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Approved

Sen. Elizabeth Dole, Chair