OFFICE OF THE UNDER SECRETARY OF DEFENSE
4000 DEFENSE PENTAGON
WASHINGTON, DC 20301-4000

PERSONNEL AND
READINESS

OCT 19 2011

The Honorable Carl Levin
Chairman
Committee on Armed Services
United States Senate
Washington, DC 20510

Dear Mr. Chairman:

The enclosed report responds to section (sec.) 744 of the John Warner National Defense Authorization Act for Fiscal Year 2007, P.L. 109-364, which directed the Department of Defense (DoD) to: 1) establish a panel to be known as the Traumatic Brain Injury (TBI) Family Caregiver Panel; 2) develop coordinated, uniform, and consistent training curricula to be used in training family members in the provision of care and assistance to members and former members of the Armed Forces with TBI; 3) disseminate the curricula and have the DoD and Department of Veterans Affairs (VA) report on the progress; and 4) evaluate the curricula before providing a final report to the committees on Armed Services and Veterans Affairs of the Senate and House of Representatives. We have submitted two interim reports to document our progress with implementing actions one through three under sec. 744. This letter transmits our final report in response to this statute. This issue falls under my purview and I apologize for the delay in submitting this response.

The enclosed report was developed by the Defense Veterans and Brain Injury Center with VA concurrence. It provides analysis and recommendations of information collected from July 2010 to June 2011 on the curricula, "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans." The cost to develop, publish, and distribute the training curricula was $292,640. Through DoD and VA collaboration, there has been significant improvement in the quality of TBI education and care provided for Service members and veterans. The family caregiver training materials can be found at the following website: www.dvbic.org/Families---Friends/Family-Caregiver-Curriculum.aspx. A similar letter is being sent to the Chairmen of the congressional defense committees and the committees on Veterans Affairs.

Thank you for your interest in the health and well-being of our Service members, veterans, and their families.

Sincerely,

Jo Ann Rooney
Principal Deputy

Enclosure:
As stated

cc:
The Honorable John McCain
Ranking Member

OFFICE OF THE UNDER SECRETARY OF DEFENSE
4000 DEFENSE PENTAGON
WASHINGTON, DC 20301-4000

PERSONNEL AND
READINESS

OCT 19 2011

The Honorable Howard P. "Buck" McKeon
Chairman
Committee on Armed Services
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Chairman:

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Thank you for your interest in the health and well-being of our Service members, veterans, and their families.

Sincerely,

Jo Ann Rooney
Principal Deputy

Enclosure:
As stated

cc:
The Honorable Adam Smith
Ranking Member

OFFICE OF THE UNDER SECRETARY OF DEFENSE
4000 DEFENSE PENTAGON
WASHINGTON, DC 20301-4000

PERSONNEL AND
READINESS

OCT 19 2011

The Honorable Patty Murray
Chairman
Committee on Veterans' Affairs
United States Senate
Washington, DC 20510

Dear Madam Chairman:

The enclosed report responds to section (sec.) 744 of the John Warner National Defense Authorization Act for Fiscal Year 2007, P.L. 109-364, which directed the Department of Defense (DoD) to: 1) establish a panel to be known as the Traumatic Brain Injury (TBI) Family Caregiver Panel; 2) develop coordinated, uniform, and consistent training curricula to be used in training family members in the provision of care and assistance to members and former members of the Armed Forces with TBI; 3) disseminate the curricula and have the DoD and Department of Veterans Affairs (VA) report on the progress; and 4) evaluate the curricula before providing a final report to the committees on Armed Services and Veterans Affairs of the Senate and House of Representatives. We have submitted two interim reports to document our progress with implementing actions one through three under sec. 744. This letter transmits our final report in response to this statute. This issue falls under my purview and I apologize for the delay in submitting this response.

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Thank you for your interest in the health and well-being of our Service members, veterans, and their families.

Sincerely,

Jo Ann Rooney
Principal Deputy

Enclosure:
As stated

cc:
The Honorable Richard Burr
Ranking Member

OFFICE OF THE UNDER SECRETARY OF DEFENSE
4000 DEFENSE PENTAGON
WASHINGTON, DC 20301-4000

PERSONNEL AND
READINESS

OCT 19 2011

The Honorable Jeff Miller
Chairman
Committee on Veterans' Affairs
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Chairman:

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Thank you for your interest in the health and well-being of our Service members, veterans, and their families.

Sincerely,

Jo Ann Rooney
Principal Deputy

Enclosure:
As stated

cc:
The Honorable Bob Filner
Ranking Democratic Member

REPORT TO CONGRESS

""Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans"

Training Curricula for Family Caregivers on Care and Assistance for Members and Former Members of the Armed Forces with Traumatic Brain Injury

Preparation of this study/report cost the Department of Defense a total of approximately $2,360 in Fiscal Years 2010 - 2011.

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## EXECUTIVE SUMMARY

Section 744 of the John Warner National Defense Authorization Act for Fiscal Year 2007 (P.L. 109-364) directed the Department of Defense (DoD) to establish a "Traumatic Brain Injury Family Caregiver Panel" to develop coordinated, uniform, and consistent training curricula to be used in training family members in the provision of care and assistance to members and former members of the Armed Forces with traumatic brain injuries.

In April 2007, the Defense and Veterans Brain Injury Center (DVBIC) was tasked with providing programmatic and logistical support to develop the guide, ensure content accuracy, and implement and maintain the guide. DVBIC went about fulfilling its mission through ongoing collaboration with the Department of Veterans Affairs (VA), civilian health partners, local communities, families and individuals with traumatic brain injury (TBI). In 2008, the panel voted unanimously that DVBIC be the responsible agency for the dissemination and maintenance of the curricula. The curricula were fashioned into a guide, "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans," endorsed by the Defense Health Board, briefed to various DoD and VA stakeholders, approved by the Services and the Force Health Protection Council, and publicly released in April 2010. The Family Caregiver Panel stipulated that providers were to be trained on the curricula content prior to dissemination to caregivers of injured Service members. Training of providers and dissemination of the guide began in July 2010.

This report provides a summary of the avenues leveraged to advertise the curricula content and availability, efforts to sustain and improve on provider training, guide distribution, demographics, focus groups, and outreach efforts between July 2010 and July 2011. Additionally, the feedback and recommendations made by focus groups, subject matter experts (SMEs), the Defense Health Board, and the Force Health Protection Council also are provided. They include a reorganization of the guide layout, the development of materials for Spanish speakers, and the development of online applications.

DVBIC will continue to collaborate with both DoD and VA health care systems, as well as leaders from both departments, to improve training and effectively implement the guide in a coordinated manner. The family caregiver training materials can be found at: www.dvbic.org/Families---Friends/Family-Caregiver-Curriculum.aspx.

## PURPOSE OF REPORT

Due to the present conflicts in Afghanistan and Iraq, members of the United States Armed Forces are one of the largest populations at risk for TBI. Family members and loved ones are instrumental to the recovery of Service members and Veterans who have sustained a TBI. In December 2006, Congress took action to support caregivers by including in the John Warner National Defense Authorization Act (NDAA) for Fiscal Year 2007 a section 744 called, "Training Curricula for Family Caregivers on Care and Assistance for Members and Former Members of the Armed Forces with TBI." The Act directed the Department of Defense to establish a "TBI Family Caregiver Panel" to develop coordinated, uniform, and consistent training curricula to train family members in the provision of care and assistance to members and former members of the Armed Forces with TBIs. The curricula, "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans," also referred to as the Family Caregivers Guide (FCG), are the product of this panel. One year after development of the curricula, DoD and VA were required to provide recommendations for the improvement or update of the training curricula. This report is a follow up to the 2010 interim report that stated this report would provide general demographic characteristics of the Service members, Veterans, and family that received the FCG, impressions and responses to the FCG, as well as recommendations for the improvement, maintenance and sustainment of the FCG.

This report describes the progress on the training curricula one year after the development and implementation of the guide.

## I. PROGRESS FROM JULY 2009 TO JUNE 2010

In July 2009, the final draft of the guide was completed and titled by the TBI Family Caregiver Panel as "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans," The target population for the guide is family caregivers of Service members and Veterans who sustained a moderate, severe, or penetrating TBI. It is written at an eighth-grade literacy level, with pictures and family caregiver experiences woven throughout the guide.

The FCG is organized into four modules with color-coded tabs for easy navigation and includes a Caregiver's Companion. Module 1 provides information on basic anatomy and physiology of the brain, the mechanisms of TBI, and the implications of injury to various areas of the brain. It is most helpful during the acute treatment phase. Module 2 provides information about the possible effects of TBI on the physical, cognitive, emotional, and behavioral functioning of the individual and provides guidance on symptom management. Module 3 focuses on the needs of families, and includes tips to avoid caregiver burnout. Module 4 provides an overview of the military and Veterans' health and benefits systems. The Caregiver's Companion is a separate soft-sided binder containing information needed on a daily basis such as military terms and medication logs. The FCG is available in print and on the Internet.

It was critical to obtain consumer feedback before finalizing the guide to assess caregivers' responses to the size, presentation, and content of the guide. Seven professionally led focus groups, consisting of 23 participants, were conducted in August 2009. A subcommittee of the TBI Family Caregiver Panel identified the focus group sites: James A. Haley VA Medical Center, Tampa, FL (two focus groups); Walter Reed Army Medical Center, Washington, D.C. (one focus group); Naval Medical Center San Diego, San Diego, CA (one focus group); Womack Army Medical Center, Fort Bragg, NC (two focus groups conducted); the final focus group took place via teleconference with those participants who had not been able to attend the in-person group near them. Family caregivers who participated in the focus groups had provided care from two months to ten years for Service members or Veterans with a moderate or severe TBI. The caregivers were predominately female, most were spouses, a third were mothers, and there were three male participants.

Focus group comments revealed that the guide provided an emotional benefit to caregivers by acknowledging their importance and the challenges of their role. Focus group recommendations improved the FCG, e.g., including the addition of tabs to demarcate each module, and providing the guide in its entirety rather than distributing it in sections (as originally suggested for fear of overwhelming the caregiver). The TBI Family Caregiver Panel endorsed the FCG at its October 2009 meeting. Additionally, the following approvals assured full visibility and endorsement of the FCG: the Defense Health Board, November 2009; Assistant Secretary of Defense for Health Affairs (ASD (HA)), January 2010; the Under Secretary for Health, VA, February 2010; and the Force Health Protection Council, Office of the ASD (HA), April 2010. At the November 2009 meeting,

the Defense Health Board unanimously endorsed the guide, and the maintenance and dissemination plan recommended by the TBI Family Caregiver Panel. There were two key components to the dissemination plan: 1) providers would personally give the guide to family caregivers, and 2) those providers would be trained on the FCG before being authorized to begin dissemination to caregivers. The panel voted unanimously to recommend that DVBIC be the responsible agency for the dissemination and maintenance of the FCG. The TBI Family Caregiver Panel later endorsed the collaboration of DVBIC and the Center of Excellence for Medical Multimedia (CEMM), which initially hosted the FCG on their website. Because the DVBIC website is a well-known resource organization for TBI in the military, a link was established on the DVBIC website. The Services and the Veterans Health Administration (VHA) identified personnel to receive the training necessary to be authorized to disseminate the curricula to caregivers. Training for providers began in July 2010.

## II. PROGRESS FROM JULY 2010 TO JULY 2011

Over the course of the past year, the requirements and intent of section 744 have been fulfilled through progression of activities related to the "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans." Examples of the activities are listed below.

### A. Training

Training was provided to those who were identified as "providers" in the Marketing and Dissemination Plan brief given to the Defense Health Board in October 2009. This included staff from DoD and VA, including but not limited to Federal Recovery Coordinators (FRCs), DVBIC Regional Care Coordinators (RCCs), Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) case managers, and social workers (see Appendix II for full breakout). Training is intended to assure that the providers deliver the FCG in a way that supports but does not overwhelm families, and is used at appropriate intervals during the TBI recovery process. Provider training is delivered via an hour-long PowerPoint presentation with in a question-and-answer format.

In accordance with training and distribution guidelines, providers were to supply education on the entire FCG to caregivers of injured Service members as soon as possible. The content of each module addresses the caregiver's need or readiness for increasing levels of information over five separate sessions. Though instructed to disseminate "as soon as possible," providers are instructed that the timing of distribution should not supersede sound clinical judgment based on individual family needs. The FCG is a tremendous amount of information to give to caregivers who may already be struggling with their loved one's injuries. Provider training includes emphasis on the importance of timing the FCG dissemination to ensure that the caregivers are prepared to absorb the information.

#### Analysis

As of June 2011, 814 guides were ordered and 579 providers were trained through 17 separate trainings on the dissemination of the FCG. The majority (80.1%) were VA representatives. Going forward we will work with DoD and VA leadership to clarify which personnel require training and how best to implement training to ensure that the appropriate personnel have received the necessary education.

### B. Website Traffic Data

On April 15, 2010, "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans," was posted on: www.traumaticbraininjuryatoz.org, with a link from www.dvbic.org. This website is sponsored by the CEMM, located at the Air Force Academy in Colorado Springs, Colorado. The TBI Family Caregiver Panel recommended CEMM host the guide and develop a multimedia companion to the print guide within the Traumatic Brain Injury: The Journey Home

section of the website. The multimedia companion to the print guide was posted on this site on June 30, 2010.

### Analysis

Data gathered on the FCG website via Google Analytics provides information about the number of visitors to the site and the number of page views to help gauge traffic and popularity trends. Analysis of this data shows that from July 2010 to June 2011, the vast majority (75.3%) of the total visits (3,982) to the Caregiver Journey Landing page were unique, and even more (80.5%) of the total visits (3,165) to the PDF versions of the Family Caregiver Guides were unique.

### Future Improvements

People use the internet to reach information and resources that might be helpful, thus the use of technology plays an essential role in the education and distribution of the FCG.

Recommendations to improve the effectiveness of technology include:

- Changing the title of the webpage that houses the FCG at the CEMM website from "Caregiver's Journey" to "Family Caregiver Guide" so people can find it quicker
- Create a text version of the FCG hosted on the CEMM Website
- Create a feedback form on the website through which to comment on the FCG
- Develop technology to allow for access of FCG information through mobile platforms and e-reader applications

## C. Briefings and Site Visits

DVBIC staff conducted briefings and site visits with providers at military treatment facilities to increase awareness of the FCG. Briefings consisted of a 20-minute introduction to the program, provided an overview of the background, development and distribution process of the FCG. Site visits were conducted to discuss the implementation process of the FCG at clinical sites. Outreach efforts to military and civilian providers, as well as to caregivers have been successful and well received.

## D. Caregiver and Provider Focus Groups

To obtain feedback from key stakeholders on this program following distribution and implementation of the program, two sets of focus groups were held separately with providers and caregivers.

### Provider Focus Group Analysis

All providers were very positive about the guide. They appreciated the comprehensive information available in one place and expressed that the quality construction of the guide

provided an emotional benefit to caregivers by acknowledging their importance and the challenges of their role.

**Key Findings from Provider Focus Groups Related to the FCG**

- The FCG provides caregivers an effective tool for navigating the recovery process with a sense of hope
- The FCG is an engaging and high quality product. It is well designed and organized, with an appealing layout, fonts, colors, and an effective use of graphics
- The FCG empowers caregivers and should be introduced to families early in the recovery process
- The quality construction of the FCG communicates that the content is important

**Caregiver Focus Group Analysis**

All the caregivers were positive about the guide. They appreciated the comprehensive information available in language tailored to families. The caregivers who participated in the focus group received the guide within the past year and consider themselves to be "veteran caregivers." For these individuals, the FCG is a resource they keep around but don't refer to regularly; however, they agreed that the FCG would have been great to have had when the Service member first suffered a TBI. Caregivers expressed that while the magnitude of the caregiving experience is hard to convey in a document, the scope and quality of the guide effectively expresses the immensity of the challenge of caregiving without being overwhelming. The majority of caregivers who participated in the focus group stated that provider follow-up was not provided after the guide was initially presented.

**Key Findings from Caregiver Focus Group related to the FCG**

- The FCG appears to be a useful tool that validates caregivers' experiences and would have been of great benefit when their Service member first sustained the TBI
- The FCG is a resource that veteran caregivers refer to less than those whose family member has a more recent injury
- The FCG is significantly more useful when families receive an in-person orientation on how to use it
- The Caregiver's Companion is a vital resource
- The FCG page design is effective, but the flow of information could be improved

## III. SUMMARY OF PLANNED IMPROVEMENTS TO FAMILY CAREGIVER GUIDE

Over the course of the past year, the requirements and intent of section 744 have been fulfilled through progression of activities related to the "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans." DVBIC has taken the data and feedback from various activities to develop actions for improving the FCG.

The following actions will be taken based on the feedback received:

- Work with DoD and VA leadership to develop strategies for training and implementation of the FCG that is efficient, effective, and coordinated between Departments
- Include the FCG in the current Caregiver Support Training Program through the VA
- Supply guidance and best practices to providers on how to deliver the FCG
- The FCG will be provided in doses, beginning right away with continued follow up

The following actions will be taken, provided there are adequate resources:

- Develop online training for providers to access the training and allow for augmented support and understanding of the FCG
- Create and implement provider review of training to gather feedback on the current training program
- Streamline access to the online materials from the CEMM website with appropriate labels and snapshots of the guide
- Develop technology to allow for access of FCG information through mobile platforms and e-reader applications
- Develop a working group of subject matter experts in order to include more information on balancing family needs and TBI care and to convey the immensity of long term TBI care
- Incorporate multimedia into the guide, to appeal to different learning styles
- Develop a Spanish version of the guide
- Organize the guide by stages of recovery

## IV. CONCLUSION

DoD has developed coordinated, uniform, and consistent training curricula to train family members in the provision of care and assistance to individuals with TBIs through the "Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans," also referred to as the Family Caregiver's Guide. Training sessions, briefings, and community outreach activities have been conducted in an effort to educate and empower providers and family members regarding the provision of care and assistance to members and former members of the Armed Forces with TBIs. Through DoD and VA organizational collaboration, there has been significant work on improving the quality of TBI education and care provided for Service members and veterans.

DVBIC encourages Headquarters-directed training and publicity to ensure that the delivery of the guide and the training of the caregiver are in place to best serve our Service members, Veterans, their families, and caregivers. DVBIC is firmly committed to working with our colleagues within DoD and VA to ensure that every family caregiver receives training in the provision of care and assistance to members and former members of the Armed Forces with moderate, severe, or penetrating TBIs.

## APPENDIX I - FAMILY CAREGIVER GUIDE TRAINING SESSIONS TO PROVIDERS

| Date | Venue/Location | Number of Participants |
|---|---|---|
| July 14, 2010 | Supporting Veterans at Home Conference, Arlington, VA | 92 |
| July 30, 2010 | WRAMC, Washington, DC | 4 |
| August 31, 2010 | DVBIC, Washington DC | 56 |
| September 16, 2010 | DVBIC, Rockville, MD | 2 |
| October 5, 2010 | National Navy Medical Center (NNMC), Bethesda, MD | 8 |
| November 15, 2010 | Teleconference for Brook Army Medical Center (BAMC), Rockville, MD | 7 |
| November 18, 2010 | Federal Recovery Coordinators (FRCs) Training, Bethesda, MD | 23 |
| December 2, 2010 | Teleconference for Landstuhl Regional Medical Center, Germany | 1 |
| December 16, 2010 | Regional Care Coordinators (RCCs) Training Tampa, FL | 17 |
| January 19, 2011 | WRAMC, Washington, DC | 2 |
| January 28, 2011 | Teleconference For VA | 112 |
| February 7, 2011 | Teleconference For VA | 151 |
| February 15, 2011 | Teleconference For VA | 66 |
| April 8, 2011 | Teleconference For VA | 12 |
| April 22, 2011 | Teleconference For VA | 1 |
| May 19, 2011 | Teleconference For VA | 12 |
| June 1, 2011 | Teleconference For VA | 13 |

## APPENDIX II - PROFESSIONAL CATEGORIES OF PROVIDERS TRAINED ABOUT FAMILY CAREGIVER GUIDE

| | |
|---|---|
| • Federal Recovery Care Coordinators | • Poly Trauma Case Mangers |
| • OEF/OIF Program Managers | • TBI Case Managers |
| • Polytrauma Nurse Liaisons | • Nurse Case Managers |
| • DoD/VA Nurse Liaisons | • Chaplains |
| • DVBIC Recovery Care Coordinators | • TBI Program Managers |
| • Deputy Director of Health for the VA | • Inpatient and Out Patient Social Workers |
| • Outpatient Case Managers | • Neuropsychologists |
| • Nurse Practitioners | • Psychologists |
| • Physician Assistants | • Caregiver Support Coordinators |