



# Defense Health Board Meeting

## December 15, 2008



# Traumatic Brain Injury Family Caregiver Panel Update

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# Presentation Objectives

- Review purpose of the TBI Family Caregiver Panel
- Review curriculum development process over course of three panel meetings to date
- Describe modules, content, progress
- Review timeline
- Outline agenda for January 2009 panel meeting



# National Defense Authorization Act of 2007 (NDAA), Section 744

- Mandated the establishment of a 15-member 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.”



# National Defense Authorization Act of 2007 (NDAA), Section 744

- Law stipulates that certain categories of individuals must be included on the panel:
  - medical professionals specializing in TBI (combat TBI as well) including psychologists with expertise in the mental health treatment and care of TBI
  - family caregivers and representatives of family caregivers or family caregiver associations
  - DoD & DVA health & medical personnel with expertise in TBI
  - experts in the development of training curricula
  - family members of members of the Armed Forces with TBI
- Panel members were appointed after receiving DoD and White House approval on 6 March 2008



# DVBIC/DCoE Role

- Provide programmatic and logistical support to ensure
  - Development of curricula according to congressional mandate
  - Content accuracy
  - Implementation, evaluation and ongoing effort for family caregiver education



# Tasks of the Panel

- Review literature and develop an evidence-base for the curricula
- Develop consistent curricula for TBI caregiver education
- Recommend mechanisms for the dissemination of the family caregiver curricula throughout DoD and VA



# Panel Meetings

- First organizational meeting held 9-10 January 2008
- Second meeting held 17-18 June 2008
  - Included Town Hall for all Stakeholders
- Third meeting held 13-14 November 2008
- Next meeting 8-9 January 2009

# Town Hall Meeting

- Wide dissemination of meeting via list serv, broad agency announcements, electronic flyer, postings, etc.
- Web streamed
- Represented organizations included:
  - Maryland BIA
  - The Quality of Life Foundation
  - VA Office of Chaplain Affairs
  - American Psychological Association
  - Mental Health Association of Montgomery County, MD
  - VA Medical Center
  - WETA
  - The Office of Senator Clinton
  - JBS International
  - TRICAE Management Activity
  - Department of HHS (Office on Disability)
  - BIAA
  - AMRPA

# Selected Inputs From Town Hall

- Family caregivers from prior conflicts want to mentor today's family caregivers.
- Emphasize hope for recovery from TBI.
- Provide success stories of service members from diverse backgrounds who sustained severe, moderate, and mild TBI. Family caregivers (parents and spouses) are encouraged by these models.
- TBI survivors want more assistance in obtaining meaningful work. They do not want to be relegated to "mail room" type activities.
- Families want strategies to prevent burn out.
- Not everyone has a family caregiver



# November 2008 Panel Meeting

- 18 of 22 panel members attended, as did 8 DVBIC staff and both contracted writers
- Presentation by DoD Center of Excellence for Medical Multimedia (Lt Col Mauffrey); [cemm.org](http://cemm.org)
- Module work groups formed with health education writers available and DVBIC staff assigned to facilitate; module work group membership diverse and representative



# Modules

- Module 1 - Introduction to TBI (learning about the brain, causes and types of TBI, acute care issues, possible complications, recovery process, helpful suggestions)
- Module 2 - Understanding Effects of TBI and How Family Members can Help (physical, cognitive, communication, behavioral, and emotional effects; related practical strategies)



# Modules

- Module 3 - Becoming a Family Caregiver for a Service Member/Veteran with TBI (starting the journey, caring for your service member/veteran, caring for yourself, helping children cope, addressing family needs, everyday issues, planning for the future, becoming an advocate, finding meaning in caregiving)



# Modules

- Module 4 - Navigating the System  
(recovery care, eligibility for compensation and benefits, compensations, rehabilitation medical support, entitlements & benefits related to employment and community reintegration)



# Modules

- Majority of meeting devoted to module work groups, considerable progress towards refining content during meeting
- Groups identified a member to serve as “lead content oversight”
- These individuals in frequent contact with module members, health writers, DVBIC staff, and panel chair since meeting; progress towards content refinement continues



# November 2008 Panel Meeting

- Tone of hope, accessibility, supportive language, proper reading level all deemed important
- Mild TBI - Further discussion needed.
- Print curriculum likely to be finished first. Next, a multimedia format will be developed.



# Timeline

- **5 Dec. 2008** Content to writers
- **22 Dec. 2008** Final modules to panel
- **8-9 Jan. 2009** Panel meeting
- **Feb.-Mar. 2009** Predecisional Pilot of Curriculum
- **April 2009** Revision of Curriculum based on Pilot
- **May-June 2009** Print and disseminate curriculum
- **July 2009** Prepare final report for DHB



# January Panel Meeting Agenda

- Final review of content prior to pilot
- Determine who will write curriculum preface
- Finalize vignettes, finalize graphics
- Finalize multimedia formats for curriculum
- Develop pilot/evaluation plan
- Develop communication and distribution plans
- Determine VA, DoD, or other clearance requirements
- Identify entity responsible for updating curriculum



# Benefits of Curriculum

- Uniform resource for caregivers through:
  - Consistent message
  - Tools for coping and gaining assistance
  - Giving hope while navigating life after TBI
- Curriculum will:
  - Be informative and accurate
  - Provide self management skills
  - Teach skills for communicating with health care and other teams
  - Be user friendly and culturally appropriate
  - Be based on real life needs and experiences



# TBI Family Caregiver Panel

- Questions?