

DEFENSE HEALTH BOARD
Traumatic Brain Injury Family Caregiver Panel
Organizational Meeting

January 9 - 10, 2008

Hilton Silver Spring
Silver Spring, Maryland

Wednesday, January 9, 2008

The January 2008 organizational meeting of the TBI Family Caregiver Panel opened at 8:15 a.m. with a welcome and comments from Lt. Col. Michael S. Jaffee, MD which set the tone for the meeting. Lt. Col. Jaffee, MD also explained the status of panel appointments and the meaning of that for the conduct of the meeting. This Congressionally mandated panel includes candidates named by the Secretary of Defense for final approval by the White House. While appointments are still pending, the TBI Family Caregiver project is moving ahead. Because of that, the January meeting was held for organizational purposes. Through the meeting participants were not able to take action by vote, they worked on a consensus basis, reporting general areas of agreement as well as dissenting points of view relating to the curriculum development.

After introductions, Project Coordinator Maraquita Hollman, MPH reviewed the agenda, goals and objectives for the meeting. Meeting participants then heard presentations from subject matter experts to prepare them for their roles as panel members and to provide grounding information on the subjects of traumatic brain injury and the experiences of caregivers. Slides of all presentations were made available to panel members through the Project Coordinator. The presentations covered the following subjects.

- **TBI Overview**
- **Ethics Briefing**
- **Literature Review**
- **Compassion Fatigue**

TBI Overview

**Kathy Helmick, MS, CNRN, CRNP and Deputy Director
Clinical and Educational Programs, Defense and Veterans Brain Injury Center
at Walter Reed Army Medical Center**

Ms. Helmick's presentation defined TBI as having some injury to the brain that results in an alteration of consciousness (AOC). She covered terminology and diagnostic scales, patterns and trends, five core components of TBI education, and current issues in TBI. The presentation generated discussion about TBI

classification, terminology, and developing knowledge in the physiology of combat blasts as one of multiple modalities of combat-related injury.

Ethics Briefing

Paul Bley, TMA from the Office of Special Counsel.

Mr. Bley reviewed all relevant regulations that frames the actions and limits on White House appointed panels. These included:

- Title 18, US Code, Chapter 11,
- Executive Order 12,731 (Do's and Don'ts),
- Joint Ethics Regulations – DoD 5500 7-F,
- 5 C.F.R. Parts 2634, 2635, 2637, and 2650, and
- PB-7/681-6012.

Mr. Bley is available through Col. Roger Gibson for ethics questions and can be reached via email at paul.bley@tma.osd.mil.

Literature Review: The Experience of Caregivers of Military Personnel with Traumatic Brain Injury **Mary Car-Blanchard, PHD**

Dr. Car found that while considerable research exists on the consequences of TBI in civilian populations, there is little related to their caregivers. She found no research into caregivers of military personnel with TBI and no strong research to promote a specific caregiver intervention or training program. Her review did reveal patterns in the caregiver experience which she presented. She also presented findings on:

- the impact of behavioral aspects of TBI on the caregiver,
- issues specific to spouses as caregivers,
- the impact of differences relating to race and ethnicity, and
- caregiver needs at various points on the continuum of recovery of a patient with TBI.

Compassion Fatigue

LCDR Pamela Herbig

Psychiatric Mental Health Specialist

National Naval Medical Center

LCDR Herbig's presentation defined compassion as follows: *an emotion that is a sense of shared suffering most often combined with a desire to alleviate or reduce the suffering of another, to show special kindness to those who suffer.* Her presentation covered: who is vulnerable for compassion fatigue, risk factors, effects of compassion fatigue, institutional costs, protective factors, and self care strategies.

DISCUSSION: TBI FAMILY CAREGIVERS

Dr. Car's presentation prompted a spontaneous discussion that involved participation from many meeting participants. Three themes were identified in this discussion: (1) types of information that caregivers need and information that should be provided; (2) How caregivers get the information: internet, in person, paper, video, role playing, social setting, sharing stories; (3) Training that caregivers need: where to get help. The following are a sample of the comments from that discussion:

- Nothing [from the presentations] is a mystery to me. I hope the committee will talk to the families. (This comment was offered from a participant who actually was a family caregiver of a servicemember who received a severe TBI and passed away.)
- Military Officers of America has done a lot on TBI. There is a lot of movement toward expanding care, along the lines of Dr. Car's presentation.
- Bethesda's Institute for Family Care located at Bethesda National Naval Hospital has developed a helpful guide titled "Through the Eyes of the Patient." This allows the voices of the family and patients to be heard, so that Hospital staff knows what their concerns are so they can be mitigated.
- The curriculum needs to be focused on the needs of the family caregiver but be specific to traumatic brain injury and be targeted towards the military population.
- Numerous caregiver organizations exist (i.e. Family Caregivers Alliance) that can assist with general caregiver information; however, caregiving as it relates to traumatic brain injury is a "new frontier" in the sense that there is not a lot of research on this specific topic.
- What is produced by this committee must be in compliance with the Congressional Mandate, since mandates a curriculum that can be used by family caregivers who are caring for former and current service members who have sustained a traumatic brain injury.
- I am hearing a lot of good practices from other caregiver programs that we could pick and choose, and roll them into our program, and give it a military focus for the military family.
- Family adjustment to TBI can take 3 yrs or more in order to accommodate the injury to the family's system. At each stage, the family needs specific types of intervention. Theme: The curriculum should reflect the stages in the family care experience as it relates to traumatic brain injury.

- We have discussed severe TBI, but we also need to address mild to moderate TBI. Just because something is classified as mild TBI, that doesn't mean that there is no or only mild disability.
- A lot of people initially diagnosed as severe might recover, and later have a mild TBI diagnosis, and they will still need care. So our output should reflect the needs for the mild and/or later recovery period.
- It's important to have a "*place*" where people can get group support, counseling, etc. The family caregivers need to have a place where they can get together and share their feelings and thoughts, and also vent their emotions. These places should offer a quiet reflective environment.
- We need to remember that the smaller MTF providers will not have the same resources; so I like the idea of a computer website in order to provide information to more remote areas. The website would contain information about resources that caregivers could access.
- Also, note that rural caregivers may or may not have access to high speed internet. How will we meet their needs? – There is a way to do that: the US has up to 2000 National Guard Armories, which can provide resources for people to access their needs. We could request that those Armories be opened up; they all have internet connectivity.
- In practice, there is also a way to establish internet connection if a need is established. There just needs to be a satellite connection set up.
- We need to make sure that whatever we put together uses all different forms of media: verbal, electronic, paper.
- Caregivers prefer someone to talk to about their needs/concerns instead of sorting through written material.
- Pamphlets and handouts don't work; the caregiver really needs a face-to-face interface, and an advocate who can guide you through the next step. Both the caregiver and the family need a person to guide them.
- Is there a way for us to design a program for that one-on-one interaction between the caregiver and TBI family members? We need to have a "needs assessment strategy" for that purpose.
- Caregiver curriculum exist with general caregiver information that can be modified for traumatic brain injury – "we don't need to re-invent the wheel."
- In the civilian sector, we agree at the Mayo Center that an individual should be on staff at the Center to provide tailored care to individual needs. Our model:

have midlevel practitioners – nurses, and so forth (not counselors) -- be available to the patient and the family. That there is one face, one person to call, who is available throughout the process.

- DoD and DOL have a joint project that will provide information for TBI into a resource directory that will be available to service members' families. The directory will be at an interagency website, at DOL. So rather than creating a different information resource, this panel could put information on that site.
- Need to balance reading material with hands-on/interactive tools for caregivers.
- Regarding what should be included in our information. It would be great if it had specific chapters devoted to the continuum of TBI (mild, moderate, and severe).
- The Mayo Clinic recommended a warmline/hotline so that caregivers could have someone to communicate with since personal contact is very important in caregiving situations.
- Night time resources are critical since this is the time when caregivers may feel overwhelmed by the responsibilities of care giving and really feel the need to talk to someone.
- Could we create a caregiver to caregiver forum? So that there could be sharing of info from expert to expert.
- It is very hard to get those caregivers that care for individuals with mild TBI to group sessions. While the servicemembers with mild TBI may cut the strings (from the facility) and have more independence, the family of the patient still needs attention. That attention to the family will take place longer than 3-4 years.
- We have been focusing on what happens when the family is with the patient in the hospital; but we also need to focus on what happens after the servicemember is discharged and transitioning back to everyday life, perhaps some vocational rehabilitation guidance is also needed.
- 80 percent of [servicemembers with] mild TBI who are outpatient have never had any treatment tailored to TBI. The large numbers of our concerns are going to be walking off the street and looking for care. Remember that the problems arise about 6 months to a year after discharge – they cannot hold a job, they are irritable, and so forth – and the family members need assistance with that issue. I think we should develop a product that will help families in that situation.
- As a panel, our job is to help the family get what they need. So I agree we need to focus on what kind of resources we can distribute to all MTFs.

- Re: legislation, Sec. 744, talks about assistance to family members, so forth. We may be able to modify the VA's spinal cord injury program to meet the needs of TBI patients and families. We need to provide training to the families while they are at the rehab center, and also when the families return home.
- Cognitive rehabilitation is not covered by insurance companies and one must navigate the military health care system for cognitive rehabilitation to occur. It is recommended that cognitive rehabilitation be mentioned in the curriculum.
- A lot of people initially diagnosed as severe might recover, and later have a mild TBI diagnosis, and they will still need care. So our output should reflect the needs for the mild and/or later recovery period. I
- Families can't get care unless they live near a VA hospital. At times even when they do live near a VA accessing care is difficult due to systematic difficulties.
- The VA added 1200 primary care community centers over the past few years with the hope that veterans can be cared for in their own communities.
- The Federal Recovery Coordinator Program is a new joint effort between DoD, VA, and HHS and is now being piloted in Tampa. The purpose of this program is to provide better coordination between clinical and non clinical case managers which will aid in the continuity of care for when a person is moving from a treatment facility to a Polytrauma Center.
- The Federal Recovery Plan is intended to address the continuum of needs of the TBI servicemember.
- What we have just described requires a "needs assessment" that must take place continually. The focus is on the caregivers' needs. We must be able to personalize and tailor the curriculum that we may provide to those needs. We also need to incorporate the caregivers into the process, to describe to us what is going on so that we can help them.
- The needs assessment is not just for the servicemember, but also for the families. The caregiver is a part of the "federal individual recovery plan." In that, the needs of all parties will be assessed. When will this happen? – The government is in the orientation phase right now with respect to providing individual recovery plans.
- Attention to servicemembers needs to take place even after the discharge from active duty.
- A very important facet is the individual parameters of the family. We need to recognize that how the family functioned before the injury can affect the

caregiver's ability to provide care to the injured service member and to deal with other family matters.

- At the VA, and Walter Reed, there is a “psychosocial evaluation” that takes place before the patient arrives; and once they get there, a comprehensive assessment takes place.
- In the seven months I was at Walter Reed, I had seven case managers – there are dynamics on the Army side that need to be fixed in order for the things we are discussing to take place. I know from our experience that a family advocate would have been very helpful in my situation. The Polytrauma Centers that the VA has have been the “lifeline” for a lot of servicemembers [implied: because they have care abilities that the other sites do not].
- There are currently 4 Polytrauma Centers, and will be a 5th at San Antonio within the next couple of years.
- I don't think we should put out anything until it has been adequately pretested, with an adequate sample of family members.
- Three themes in our discussion: 1. types of info that caregivers need, info that we should be providing. 2. How they get the information: internet, in person, paper, video, role playing, social setting, sharing stories. 3. Training that they need: where to get help, whether for themselves or others.

ORIENTATION ON CURRICULUM WRITING

A number of meeting participants had questions regarding time frames and curriculum development. Maraquita Hollman, the TBI Family Caregivers Panel Coordinator provided an overview of the time frames that exist. She explained that she is reviewing proposals from health education writers she received in response to a RFP. She expects writing to be in February and continue through March and April. The current schedule requires the curriculum to be presented to the Defense Health Board (DHS) on April 24. Meeting participants asked if she would be able to get that time frame extended, in that the panel appointments have not been made official. Ms. Hollman explained that she will take their request forward to try to get another month so that the panel members will have time, after their appointments have been made official, for needed review of the curriculum content prior to the DHB meetings.

CURRICULUM BRAINSTORMING

Before beginning this discussion, the facilitator reviewed the section of the panel's charge from Congress.

The Traumatic Brain Injury Caregiver Panel shall develop training curricula to be used by family members of members and former members of the Armed Forces on techniques, strategies, and skills for care and assistance for such numbers and former members with traumatic brain injury.

They were then asked to identify 3-5 ideas they have about the content of the curriculum and to offer them, round-robin, moving around the table to gather ideas. The following are the ideas generated from that discussion. They were tagged by the facilitator to identify groupings for a later discussion of goals and objectives. Some similar comments were grouped together.

- **We need training for the mild injuries.** Overwhelming majority of brain injury is mild brain injury. Moderate to severe is relatively easy to recognize but mild injury has to be validated; usually the family is the group that identifies the issue. The great majority of mild brain injuries, after 3-6 months, allow the servicemember to return to a baseline of normal activity. Many can return to active duty after 6-8 months. But whether or not a service-member can return to active duty depends on the nature of the duty – for example, a short-order cook went back, but an attorney could not multitask and could not return. (Focus)
- **Special problem reaching Guard and Reserve members.** Reservists' problems need to be addressed. Following up with National Guard service-members and Reservists is a particular problem. When they return from duty, they are only involved in post-deployment care for a few days, after they go back to their point of origin. Unless they have severe, acute injuries, requiring care at a military treatment facility they go back to their hometowns. The problem is that it is very difficult to fund centers in the rural areas that need to treat the returning Guard and Reserve members. With Active Duty members, we can train their families; but the Guard and Reserves' situation does not allow us to have the same access to families. (Focus)
- Separating mild and moderate-to-severe TBI. (Focus)
- Something for children of TBI injured parents. (Focus)
- Sometimes an older child will take over the role of caregiver for the family as the spouse is by the bedside. (Focus)
- Children are part of the family dynamic, and need to be addressed. For example: PBS has developed a Sesame Street video. (Focus)

- Recommendation that the product be designed to allow servicemembers to be cared for by someone who knows about and is comfortable with TBI. (Focus)
- Basic reference materials. Memory jogs. (References/Resources)
- Definitions/glossary. (References/Resources)
- Guide to the process of care delivery: Medical care. Very complex to know how to interact with Medical caregivers. (Reference/Resources)
- The titles and descriptions of the health care providers that are available: such as a neuropsychologist, neurosurgeon, neurologist. (References/Resources)
- Education on availability of facilities for treatment. (References/Resources)
- Information on support resources, local resources, explaining where to go if help is needed. (References/Resources)
- Grieving the loss of the person who was once there.(References/ Resources)
- Glossary of terms re: brain injury. (References /Resources)
- The services and VA should remain intricately involved and take ownership of their wounded servicemembers for life. (Distribution)
- VFWs work very well because victims need to communicate together. (Distribution)
- Caregiver Mentoring program (Program)
- A Hotline or a Warmline (distinguished from a hotline in that it is used not for urgent crisis situations; it also has normal business hours) for use by family. (Program)
- Coverage decisions [not so much an educational thing more of policy].
- Phases of TBI. (What to Expect)
- Family members, especially for severe TBI cases, should be provided with information regarding the disability process and what types of benefits are available through the military. The VA should be involved in writing this part of the curriculum. (What to Expect)

- Basic information on what to expect from the time a patient arrives throughout the treatment process. This would include what kind of timeline a family might expect. (What to Expect)
- Aspects and impacts of TBI: “what you will see” (What to Expect)
- A timeline for family -- especially civilians -- of what to expect, once treatment begins, from the military and the caregivers; (What to Expect)
- Encouragement to families that most patients get better (What to Expect)
- Psychosocial issues for the entire family in terms of how they may expect to be affected: for example, how the children are affected by specific issues. (What to Expect)
- Differences exist in medical care and recommendations for symptom management of TBI and PTSD (i.e. sleep instruction, options of care, recovery times) (What to Expect)
- Troubleshooting, noting common problems that can arise. (Practical/Tools)
- For the families: easy-to-read table or chart, listing the problem and what to do about the problem when it arises. (Practical Tools)
- How to deal with behavioral changes. (Practical/Tools)
- Training on how to give day-to-day care in the home. (Practical / Tools)
- Tips and tools for coping; things to post on the refrigerator. (Practical/Tools)
- Suggested activities for re-integration into family and local life: Like bowling, shopping. (Practical / Tools)
- Normalize their responses to the behavioral issues – put together a “small behavioral management program” to address, for example, what to do when a family member interrupts constantly, or hypervigilance, or driving in car for first time. Concrete information about what to do in response to challenging behaviors. (Practical / Tools)
- Communication techniques. (Practical / Tools)
- Importance of routine and how to build a routine into the family. (Practical / Tools)

- Self-assessment for caregivers (Practical / Tools)
- Instruction or Introduction on how to address lack of self-awareness after brain injury; fatigue; chemical abuse; sexuality; employment; school; driving.
(Practical / Tools)
- A “problem-solving format” – kind of a graph that families can use simply
(Practical / Tools)
- Teaching people so they can be their own advocates. (Skills)
- Which signs and symptoms are the TBI patient going to exhibit, how do those symptoms reveal themselves and when? (Skills)
- How to educate others; recognizing mild TBI and what to do when you see it; also information to employers who may recognize a cognitive deficit. (Skills)
- Education regarding caregivers’ physical health and mental health; grieving and loss; what their limits are, and who to call for help. (Self-care)
- Self-care issues: how to take care of yourself when taking care of someone who has been injured. (Self-care)
- Let the caregiver know it’s OK in the event that they find “I can’t perform this role,” and give them alternatives so that they don’t think the burden is completely on them. (Self-Care)
- Something that touches on caregiver abuse? (Self-Care)
- A “modular format” that can be tailored to specific needs (meaning tabs that you can flip through). (Format/Process)
- A mechanism should be in place that shows how much the family member has absorbed from the curriculum training and what needs to be reviewed for a more complete understanding of the curriculum. This will also give the trainer the opportunity to verify that the training content has been properly communicated. (Format/Process)
- Simulation devices or simulation centers for use by the family with respect to administration of care techniques. (Format/Process)

- Make sure that the materials are written understandably. (Format)
- Pre-testing and focus groups is really key to developing an effective product; make sure that the focus groups contain all of the services. (Process)
- Long-term care coordination (Information)
- Discussion of severity: What to do in cases of mild or severe injuries. (Information)

Thursday, January 10, 2008

Maraquita Hollman, TBI Family Caregiver Panel Coordinator opened the session and introduced Col. Angel Lugo, (Acting Chief of Staff Defense Center of Excellence for Psychological Health and Traumatic Brain Injury. On behalf of Col. Gibson and himself, Col. Lugo greeted the participants and reiterated that because panel members were still not officially appointed, that today's meeting is an organizational meeting and that they would not be able to vote on the outcome. They would be able to steer the direction of the curriculum development by consensus and later, confirm the panel's recommendations by a vote.

Ms. Hollman then turned the meeting over to Dianne Lipsey and David Clark from ADR Vantage, Inc. to conduct the meeting and facilitate and record discussions. Ms. Lipsey welcomed the group and reviewed the day's agenda.

CURRICULUM GOALS, OBJECTIVES, AUDIENCE SESSION

Facilitators distributed copies of the results of the Curriculum Brainstorming for participants to use in identifying goals and objectives and reviewed a definition of goals. Participants then selected to work in one of the following small groups to identify goals, objectives and as appropriate, the audiences for the following topics:

- **Expectations Group:** Curriculum content dealing with information to help family caregivers understand TBI, what they should expect, and where to turn for additional information.
- **Practical Tools Group:** Curriculum content dealing with practical tips and tools for quick reference and tips and materials to help TBI family caregivers:
 - gain skills needed to support their family members with TBI;
 - become more empowered working with treatment providers and others; and
 - encourage self-care.
- **Group on Curriculum Focus:** How the curriculum should be tailored to meet the needs of a broad base of TBI family caregivers; and

- **Dissemination and Format Group:** How the TBI family caregiver curriculum should be distributed and which formats the materials would be needed to facilitate that distribution.

Each group presented their goals and objectives, also highlighting the subject matter that would need to be covered to meet the objectives. Some subjects emerged from more than one group. This conveyed the importance of the subject to many of the participants. It also showed that the subject might need to be addressed in different ways to fulfill different needs, different audiences, and/or different circumstances.

The following are the points presented by each group, in some cases with minor edits for consistency.

Expectations Group: Curriculum content dealing with information and resources relating to “What to Expect”

Goals:

To provide comprehensive information *[to help TBI family caregivers know what to expect]* on administrative processes.

To provide procedural information, medical information regarding injury processes and expectations regarding treatment for TBI in DoD/VA facilities.

Objectives:

1. Military administration and VA procedures -- Med boards; who are medical providers and what are their roles?
2. Treatment options -- What are the tests and procedures people might need throughout? What are the levels and pathways of care?
3. Aspects of TBI that caregivers will see and timelines for recovery.
4. Psychosocial issues.
5. Empowerment and advocacy.
6. Encouragement and hope.
7. How the caregiver will be affected by the process -- Self-Care – What it is like for the families to go through this?

Practical Tools Group: Curriculum content dealing with practical tips and tools and skills

Goals:

Provide information, skills and tools to empower TBI family caregivers to find new levels of “normalcy” in life with family members with TBI, appropriate to their stage in recovery.

Provide access to certified, standardized TBI professional training (which would be fully funded).

Objectives:

1. Explain the Med Board process. This information would include costs and benefits of remaining on active duty and how options of care may be achieved.
2. Provide coping strategies. This would include:
 - Trouble-shooting chart;
 - Self-assessment: When to know if you are not the right caregiver and how to get a new one; how to ask for help and who to ask;
 - What typical caregivers go through; teach compensation and communication strategies;
 - Grieving the loss of a person;
 - Explanation of levels at which abuse to the caregiver occur.
3. Teach day-to-day care techniques:
 - Physical needs,
 - How to stay a member of the team so that self-medication doesn't become a problem;
 - Needs of a recovering TBI patient;
 - Activities of Daily Living.
4. Define the health care team (inpatient and outpatient); describe how to interact and partner with the health care team; describe how to be your own advocate. Educate on options for care (civilian, VA, MTF). Explain the process of care delivery.
5. Explain cognitive and behavioral changes. Provide tips for change management (sexuality, substance abuse, socializing, and so forth); provide suggested activities for reintegration into family and social life (shopping, bowling, and so forth).
6. How to assess the TBI patient's self-awareness. E.g., help with driving limitations, finances, etc.

7. Explain importance of routine. Give tools to build structure into family and community life.
8. Explain legal subject matter such as power of attorney.
9. Explain difference between TBI and PTSD: when they overlap, signs and symptoms (battle observer).
10. Provide glossary of basic TBI and military terms.
11. Resources and references.

Group on Curriculum Focus

Goal:

To provide appropriate materials to educate, train, and provide resources to TBI family caregivers across the continuum of the TBI diagnosis, treatment, and reintegration of servicemembers and veterans.

Objectives:

1. Recommendation: TBI may not be the only diagnosis (For example, brain or spinal cord injuries may exist as well.)
2. Appropriate: Individually focused *[Materials should be offered to address what the family needs at the time they need it and in a format they can most easily use.]*
3. Materials: Must be not only general materials, but also specific and would:
 - _ Include financial, social, marital, medical, spiritual information.
 - _ Be flexible: Must be changeable to accommodate the flexible role of the caregiver.
 - _ Provide a definition of caregiver that can change depending on the situation -- the servicemembers themselves, their groups, designated family members.
 - _ Legal Issues: Legal processes, HIPPA and privacy issues must be taken into account, differences between power of attorney and durable power of attorney.

- The army does not require a global power of attorney or a will. It is surprising that the power of attorney is not mandatory.
 - When servicemembers do have a power of attorney, it is not “durable,” which means that most of the time the power will expire after one year.
 - Durable powers of attorney should be encouraged.
 - Should also consider significant others; case example of a girlfriend of a TBI servicemember who needed empowerment to be able to give care.
4. Inclusive of the transition process: Must capture all of the different points of the process.
 5. Resources must be appropriate to all types of caregivers that might be involved.
 6. Must be aware that several different diagnoses can be happening at once, in addition to a TBI injury.
 7. Definition of TBI is all-inclusive on the spectrum: from severe to mild cases of TBI.
 8. Training: to provide physical and emotional training and techniques. Should include role-playing, be hands-on and include vignettes and quotes from actual caregivers highlight the information and to make caregivers feel more comfortable.

Dissemination and Format Group

Three groups: Health care providers; family members; other personnel.

Goal:

To establish a format of dissemination tailorable to the needs of the TBI family caregiver/user. The information must be: Accessible, Tailorable, Available

Objectives:

1. Accessible: Multilingual; 24/7 access; and available anywhere.
2. Tailorable: Modular and must contain an avenue for feedback and evaluation.

3. Available/Usable: Must be disseminated through available dissemination techniques. The format would consist as follows: website/URL, hotline/warmline, pamphlets, CDs, message board.
 - _ The Website:
 - Would be interactive, with a blogging system that would be accessible by anyone worldwide.
 - Users could order a pamphlet or different print materials based upon their needs and information on the website.
 - Webinars would be available, eventual goals would be web interactive abilities.
 - _ The Print/Paper information would be concise, modular, and tabbed information and simple to understand.
 - There is a concern that caregivers should not be inundated with too much paper information.
 - Users should be able to select specific topics (this fits into the “modular” paper requirement and also making sure that specific topics are listed on the website).

Comment: some people are now accessing the “caring bridge” website, which we might be able to use.

CURRICULUM OUTLINE CONSENSUS SESSION

This session was used to explore the ability to prioritize subject matter and to further organize it so that meeting participants could express general agreement with it. Participants were asked to go in groups to each of postings from the small group work and place a sticky dot beside each of five subjects they considered most important to be covered in the initial curriculum. Through this exercise, it became clear that there was a strong consensus (sense of the group) in a number of key areas:

- All subject areas identified in the goals and objectives should be reflected to some degree in the curriculum.
- All levels of severity – mild, moderate, and severe – should be addressed in the curriculum, at least to some extent. (While some participants indicated that there might be more emphasis placed on moderate to severe, a number of strong voices advocated for recognizing:
 - There are far more cases of mild TBI;

- That the unique and disabling nature of mild TBI as equally as important as addressing more severe TBI.*
- Materials must be not only general materials, but also specific. They should be designed to be flexible and changeable to accommodate changing roles of the TBI family caregiver, different needs of caregivers at different points. It should also take into account that this information may be necessary for years after the injury, maybe up to five years later.
- Some emphasis should be placed on how the curriculum materials will be used. Those who will be providing information and/or training to TBI family caregivers should be trained to assess the needs of the caregiver and respond to what that caregiver needs at the time they need it. (There was a fair amount of discussion among the participants about this: That every family will be different and not able to absorb the same information presented in the same format as others. Families should be able to “drive” their own education.)
- In terms of format, there was general agreement that there should be multiple formats for purposes of reaching people in the way they learn – reading, pictures or video, experience; and modular so that caregivers can focus on the information they need at a given time, rather than everything at once. They should be family-friendly and easy to use.
- There is a need for a uniform definition of family caregiver that reflects a broad definition of “family,” the fact that this primary caregiver may change over time, and that can be adopted for standard use across the armed services. The group generally agreed that creating such a definition should be within the purview of the TBI Family Caregiver Panel.
- Process Recommendations – A number of comments from the meeting participants related to how the curriculum should be delivered and supported to be effective with family caregivers. The following are some of those comments:
 - Families’ caregivers differ in what they need and can use. Providing information for caregivers should be a family-driven process.
 - Assess where the family is and provide the family caregiver with what they need when they need it.
 - Be prepared to “be there” when the caregiver is ready for the information.
 - Provide information in the format that the caregivers can use -- multiple formats.
 - MTF’s should have a TBI POC. There should be a 1-2 day uniform teaching course for all POC’s.
 - The caregiver really needs a face-to-face interface, and an advocate who can guide you through the next step. Both the caregiver and the family

* One participant provided a useful diagram that illustrated the importance of this point. See attachment

need a physical human guide to guide them through the recovery process of TBI.

DEFINITION OF TBI FAMILY CAREGIVER

Throughout the discussion about the curriculum, its audience, use and distribution, meeting participants came to understand that the lack of a uniform definition of TBI Family Caregivers complicated the discussion. Further there was a sense of the group that the panel should have a role in defining this term and clarifying the difference between a primary TBI Family Caregiver and others who will have a role at various points throughout the servicemember's or veteran's recovery. The group agreed to spend a short amount of time working on some preliminary wording but to continue to work on the definition as part of its contribution to the curriculum. The following is the early draft language the group developed.

Any family member or support person or persons, [who is relied on by the servicemember or veteran with TBI*], and is responsible for providing the needed level of direct care and overall well-being for that servicemember or veteran.

(Alternative language) . . . whose life is affected/restricted by a servicemember or veteran's TBI through ...

(Alternative language) . . . who assumes the primary responsibility for providing...

(Alternative language) ...that is hands-on and may range from supervision to total dependent care

All agreed to leave the definition incomplete but to include the subject as an agenda item for a future meeting.

TBI VIDEO

Mike Welsh, (SGM Retired), sustained a traumatic brain injury while serving in Afghanistan. As part of his recovery, he produced and narrated a DVD to help tell the story of TBI. He played it for the group, during the lunch break. He artfully mixed many of his several thousand still photographs of his experience in Afghanistan, with live interviews, music and narration into a powerful 14-minute program. Educators in the room were eager to get copies of it and it will be considered as part of the resources for the curriculum.

* Bracketed language might be deleted in the final language.

RESOURCES

Meeting participants often referred to materials, programs, individuals, and other resources in their discussions. The resources below were collected from the participants. In addition, a list of references submitted by Barbara Cohoon of the National Military Families Association is attached with this report.

Materials to be identified as resources for Care Givers included:

- Disabled American Veterans (DAV) website for Med. Boards
- Defense and Veterans Brain Injury Center website for “TIP” pamphlets
- DAV & Veterans of Foreign Wars (VFW) websites for assistance in applying for disability
- Carmen.Hall@VA.Gov for family care map
- Sharon.Benedict@VA.Gov for polytrauma family education manual
- Cargiver.com
- Caringbridge.Org
- “Palace Hart” program – AF
- www.armyhrc.com
- Reference story: “Where is the Mango Princess?”
- Brain Injury Association of America (BIAA) Bookstore
- Glossary of military and medical terms

Resources recommended for curriculum source materials include:

- Pauline Boss’s book
- DVBIC manual and website
- National Guard Advisors & Centers
- Army’s TBI chair teaching
- BIAUSA.org
- Lash and Associates Publishing
- North American Brain Injury Society
- TBI/Technical Assistance Center
- www.wellspouse.org
- Family Caregiver Alliance
- Kate Lorig’s book

- BIAA
- The Neurotrauma Registry
- Fort Carson's Family Caregiver's Guide
- Caringbridge.org
- Lynda Davis – Secretary of the Navy
- TBI Model Systems (NIDRR)
- Interactive Drama, Inc.

MEDIA AND DISTRIBUTION

The purpose of this discussion was to learn about resources and capability of the panel and others to distribute the curriculum and to consider what types of media would be needed. The types of media needed were well discussed in the small group sessions earlier in the day. This session then focused on the resources and capabilities available for distribution and the group produced the following list.

- VA employee education service
- "My Healthy Vet" website – ["My health e-vet"?]
- VA patient education network
- Each MTF has a public affairs office and officer, responsible for media contacts and events in their area
- DKO or AKO "defense/army online"
- "Wounded Warrior" programs through the individual services -- "Safe Harbor" in the Navy
- CDC's website and their partnerships with civilian distributive networks
- TBI state offices
- Foundations, like the Bob Woodruff Foundation
- Veterans and Military service organizations
- Family assistance organizations and services – Soldier family assistance centers which are distinct from family assistance centers
- Family Caregivers Alliance
- Fisher houses would be places to physically house curriculum and offer it; each service has its own family center alternative
- VA's Polytrauma Center website
- Employee assistance centers
- Vetsuccess.gov

- “America Supports You” website
- Reserve and National Guard regional representatives
- VFW magazines (veterans services organizations)
- USAA (insurance company that is associated with military)
- Armed Forces Radio; Armed Forces Network
- BIAA -- Brain Injury Association of America
- Reserve officers associations; Reserve enlisted associations
- American Medical Association
- Indian Health Group – (A lot of the National Guard would have access)
- NIDRR; Knowledge Translation Center at the U. of Washington
- ESGR
- National Guard Transition Assistance Advisers
- SAMSHA
- HRSA -- Health Resources and Services Association
- HOOAH
- AARP
- Medical Schools/In-service schools
- Helen Hayes/RSC/JFK and other civilian centers
- Psychiatric Associations/APA
- National Association of Psychological Health Systems
- National Rehabilitation Association
- American Nurses Association and the association representing non-unionized nurses
- APNA
- Visiting Nurses Association
- Disabled American Veterans website

CLOSING

Before closing the discussion portion of the meeting, the group reviewed business being carried forward for additional action after the meeting. These items included:

- Maraquita Hollman will post the websites where the meeting participants can look for possible language for family caregiver definition.

- Maraquita Hollman will seek permission to extend the time frame for curriculum development by a month.

The facilitators and Ms. Hollman thanked the meeting participants and the Organizational Meeting of the Traumatic Brain Injury Family Caregiver Panel closed at 2:30 pm.