

**Defense Health Board
Traumatic Brain Injury
Family Caregiver Panel Meeting**

Transcript of June 17, 2008 (Day One)

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P R O C E E D I N G S

Official Opening of the Meeting

COL GIBSON: I am Roger Gibson, Executive Secretary for the Defense Health Board. I would like to call this meeting to order. I will act as the announcer, et cetera, until we get a Chair and then once the Chair is elected, that Chair can take over and run this meeting.

We all are part of a Federal Advisory Committee to the Defense Health Board. We are a subcommittee under that board. The organizational structure that you see up there on the screen is how the Defense Health Board is put together.

All of the Federal Advisory Committees -- and there is 38 of them within the Department of Defense -- all work directly for or report directly to Secretary Gates. In the case of the Defense Health Board, the Under Secretary of Defense for Personnel & Readiness is the sponsor. He has delegated the authority to Dr. Casscells, the Assistant Secretary for Health Affairs.

The on-the-books Designated Federal Official, the person who is the liaison between the Board and the

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Department is Ms. Ellen Embrey. I am her stand-in, if you will, today. I am her water boy.

The Board consists of 25 members of the Core Board, Dr. Rev. Certain on our right. Bob, do you want to raise your hand? He is a member of the Core Board with us today. Then, you see all of those subcommittees underneath.

Of interest, the Family Caregivers Panel, when you finish your curricula, et cetera, the TBI, Traumatic Brain Injury external advisory subcommittee will take care of asking the Department periodically, what are you doing with this thing, is it working, is it not working, how are you surveying, have you had to make changes, et cetera. So, you will have another group of folks who will be able to ensure that the Department does what it is supposed to do with the product that you make.

With that, there is a couple of official things that you have to do. As the alternate Designated Official for the Defense Health Board Federal Advisory Committee and a continuing independent advisory body to the Secretary of Defense via the Assistant Secretary of Defense, I call this meeting to order.

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One of the things that the Board has a tradition that we have started, that has actually been going on for several years now, we stand for a moment of silence for the folks that we are here to serve.

[Moment of Silence.]

COL GIBSON: Thank you.

A couple of administrative issues. The presentation from the Center of Excellence for Medical Multimedia, that group is not going to be with us this morning. They are going to be here at 1 o'clock, so on your agendas, move everything up from 10:15, move it up one session and at 1 o'clock those folks will be coming in to do their presentation.

Since I don't know everybody, and I am not sure everybody else knows everybody, let's go around the room and make introductions as we get started.

[Introductions.]

COL GIBSON: As I mentioned, I am Roger Gibson. I am the Executive Secretary for the Defense Health Board and the Designated Federal Official for this meeting.

One of the requirements by Federal Advisory Committee rules is that we have a Designated Federal

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Officer at every one of these meetings.

It looks like on the agenda, Mike, you are up next.

**Welcome/Intro of Health Education Writers
and Manager Office of Educational Programs**

COL JAFFEE: Good morning and welcome back to those of us who were here in January, and I just want to make one process comment.

You may recall we didn't have the formality of the opening aspects in January, and the one big difference between January and now is in January, there wasn't final approval on the appointments from the White House for everyone serving on the panel, so we were having an organizational meeting.

But now that everybody has been fully approved and every box is checked and everyone is official, this is actually an official meeting where we are following more the formal protocol where we actually do have the right to make decisions and vote whereas before it was more for organizational and informational purposes. If you are wondering why things are a little bit different, that is the contextual difference between then and now.

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I think we got off to a good foundation in January that we are going to pick up the ball and run with and continue while we are here today, and then when we were making introductions, I just do want to again take my opportunity to introduce Meg, who just introduced herself as kind of heading up our whole education section at DVBIC, which is a pretty large and important undertaking, and has jumped right into this project of teaming up with Mary Keto [ph], who has been carrying the entire ball.

We have a couple of our additional people who are here to help support this initiative and this project. I just want to kind of point out their role. I want to welcome back Dr. Mary Car-Blanchard.

She was here with us in January and gave a very helpful overview and review of the literature with regards to educational curriculums, and she is going to be an important part of this initiative as we move on as one of the health writers that we have hired as well as a new face has just joined us, Ms. Rohret, who introduced herself before, so we welcome you and are pleased to have that level of expertise and support that can help

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translate some of the ideas that we come up with into some very helpful products.

The Center of Excellence from Medical Multimedia is here. They are going to do some travel and baggage situations is why they are changing the schedule, but to put that in context, they are, to my knowledge, the Department of Defense's only organization that is dedicated to producing medical multimedia things, and the reason that they are here is a couple. One, just want them to give us a feel for the potential of power for the multimedia format.

We had discussed last time using that, but I don't think we had yet realized or talked about what that might look like, so they are there to help us stimulate that thought process or the possibilities for multimedia.

They actually, for those who aren't aware who they are, they actually do produce excellent products, actually win industry awards, beating out a lot of universities and civilian agencies, so they have a very strong track record in this aspect.

It so happens that they have been developing a product of TBI education targeted towards family members

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and caregivers, but that may not necessarily be the same thing of a lot of the ideas that we were talking about of the family caregiver type of curriculum.

So, they are hoping to get some input from you as to how to better refine the product that they are working on and that is a launching point for further discussion as to should they augment or add onto that project to attend more to the family caregiver needs, or should they look at a second product and should that tie into this type of initiative here, and that is a decision for the Board and that is a discussion for the Board.

There is lots of different possibilities, but the main role, the main two reasons they are here is to give us a feel for the power of multimedia and to get feedback on the educational product they have, which may not necessarily be the same as what we are looking on.

I would like to review some of the objectives for the next day and a half or two days. One of the things that I am hoping we can sort of walk out of here very comfortable with is being very comfortable with who the target audience is for the curriculum, getting a handle, a good idea around the concept of what is a

caregiver, selecting the curriculum modules almost kind of on an outline, if you will, or knowing the types of information a module is going to need to pursue and develop, a feel for what the content of those modules might be.

For those of you who are aware, there is going to be a town hall this evening. We are hoping to get input from more of the patients and families as to helping us get more of an understanding for the priorities of what their needs are, not only in what they need to know, but what is the best way of delivering that information, as well as a road forward and a timeline for how we are going to kind of realize this objective and this goal.

By about 2:30 tomorrow, according to the agenda, hopefully, we will have kind of a blueprint for not only kind of knowing what we are going to do, and then the way ahead.

I started off my comments in January by really thanking everyone for their dedication and the time that they are devoting to this project, and I am thanking you again and in advance because I think when we leave here,

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we are going to set the foundation, but there is going to need to be some ongoing communication and dialogue, and that is something else I would like us to be comfortable is when we leave as to how that is going to happen, should that happen to be e-mail exchanges via teleconferences and the like, so my hope is we can also have a plan for the future and a way ahead to as these products start coming on line and getting developed with our input, being able to, in an efficient way, review, interact with one another to put our collective list in together to really synthesize and produce the very best product and program that I know we can. We have the right people in the room to do it.

So that is really kind of the aspects with laying the foundation of last time, a lot of the underlying organization, and now I really think we are going to start the real work ahead and lay that framework for the future.

I thank you again for the traveling and giving up two days of your very busy schedules for us today, and thanking you for your expertise and input as we move forward and the ongoing communication that we are going

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to have.

There will be another face-to-face meeting, but I expect that there needs to be some communication between now and then.

Once again, I can't thank you enough. We are privileged to be able to facilitate this initiative which we feel is incredibly worthwhile. As you know, Congress felt it was worthwhile. This was their initiative, this was why they thought it needed to be done.

So, with that, I will turn it over to Colonel Gibson.

Election of the Panel Chair

COL GIBSON: Meg, do you have a process to go through for the chairmanship? You are the facilitator for the meeting.

MS. CAMPBELL-COTLER: As a body of volunteers appointed by the White House, we need to have a Chair, someone who speaks for the group, who is not part of DVBIC, who is not part of the formal structure of the military, and we need for this to happen this morning, so that we can move forward in an organized fashion.

We have not really provided a balloting

situation. I think that we are hoping that we would have a nomination from the floor for an individual who is seated at the table.

I am sorry, I have really been caught unprepared for this part of the agenda, but I would like to recommend Dr. Flynn as Chair for your consideration, and I hope that we might have a vote of affirmation that Dr. Flynn would be our Chair for the remaining part of our work together.

DR. FLYNN: If I could make a comment, first of all, I am very touched that you would even consider me, and although TBI is a very big part of my life and everything, if I could, if I could just throw this out for the rest of the group, again, I am touched for the consideration.

My personal feeling is that the representative of this group, because it is for the issue of family care, there are people here at the table that have a lot more direct hands-on and expertise in the family care aspect of TBI including those who have had personal experience as family care providers.

I very humbly state that already I am involved

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in a lot of things. I don't like to take on any new responsibilities that I feel like I can't give 100 percent to, and although I will do everything I can to support this group, that is why I am here, my feeling is that the representative of the chair should be somebody who deals with family care issues on a day-to-day basis and/or has been a family care provider.

If I could, if it's okay with you, Meg, I would like to just temporarily throw out to the rest of the group is there anyone here who actually would like to have this position, would like to go for this position?

Don't be humble about it. I think if you have somebody in the group that really wants to be the Chair, wants to be the leader, and wants to be the coordinator for this group, I think that is 50 percent of the battle right there.

COL GIBSON: The good part is you have an incredibly good staff behind you as the Chair. They will be doing the heavy lifting. It is a matter of you being the leader of the group as we pursue this curricula, you know, setting up the meetings, make sure that everybody is ready to go, et cetera, they will do a great job for

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that.

Are there any other nominations, any other folks who either volunteer or want to nominate the person beside them to be the Chair? It is open to both military, civilian personnel, and non-Federal members, so anybody can, in fact, be a Chair and still fit within the Federal Advisory Committee rules.

Nominations?

[No response.]

COL JAFFEE: While that is going, while people are mulling that over, I will just say that I think that, just to clarify what the Chair does and what the Committee does is you are White House appointed advisors to the Department of Defense, so people who are in official capacities can't direct this panel, so the panel is directed by the people who are sitting here, and the Chair sort of helps organize that direction, helps assure that representatives are present at the Defense Health Board meetings to provide updates that could be done by the Chair or one of his appointees or any member of the panel or any member of the supporting staff, but just making sure that these things are attended to or getting

done and helping to kind of steer the meetings to make sure we are meeting the objectives, so that is kind of what the role is of that individual.

With that, further nominations remain open. I thought I heard someone was about to say something.

REV. CERTAIN: I am not on this panel. I am on the Defense Board, but not on this panel.

COL JAFFEE: He is a member of the formal Defense Health Board, and is serving as kind of a conduit liaison between the Subcommittee and the Board. He keeps us honest to make sure we are providing the feedback accurately.

MS. CAMPBELL-COTLER: In my experience as Executive Secretary of a board at a community level, I must say that the role of the Chair is -- the way I worked as a Chair -- is it is a collaborative process. It is important that we, as staff, are not driving the process that you, as members of the panel, are driving the process.

So, there is frequently telephone conversations, obtaining assistance in preparation for the next agenda, there is dialogue about the input we are

receiving or not receiving from panel members, and perhaps the Chair would be the person who might encourage a panel member to certainly respond to our requests for input.

But the bulk of the work is on the staff, we use the Chair as our point of consultation with the entire panel, and I believe it would not be an onerous task for anyone, I certainly would promise you that, that we and the staff would be taking over the major role of getting things done. We need someone to chair the meeting and to be our point within the point of contact for the panel members.

MAJ VOGT: I am going to nominate someone, and I hope you don't get upset. I don't remember your name.

MS. MOESSNER: Anne Moessner.

MAJ VOGT: It seems like you have got a lot of experience dealing with the family and the caregivers with your involvement at Mayo.

MS. MOESSNER: I actually do. I have frequent contact with patients and families in my critical role at Mayo and have done that for many years.

DR. FLYNN: I would like to second that

nomination.

MR. DODSON: We like Anne.

MS. MOESSNER: Thank you.

MS. CAMPBELL-COTLER: Is there any discussion?

A unanimous vote, "aye."

[Chorus of ayes.]

MS. CAMPBELL-COTLER: Thank you.

Review and Approval of January 2008

Meeting Summary

MS. CAMPBELL-COTLER: Anne, the main role right now is to review and approve the minutes, and these are not minutes per se, they are summary notes, but we do want to be sure that we have captured accurately the discussion of the meeting in January. Let us know if we have missed some important thing. These are summary notes, not verbatim notes.

MS. MOESSNER: They are in your reading packet.

MS. CAMPBELL-COTLER: I was going to say they are in their meeting packet, and we had them ahead of time, and so I don't know if I have a minute to look those over, but if there is any discussion about the minutes or the notes.

DR. FLYNN: I have a comment. This is the dangerous thing when you are on a five-hour flight, you have plenty of reading material and you tend to go over your notes more carefully.

Again, not referring to any specific page, but the theme kind of came up a couple times, I think on page 4 and page 5, again, this may have been the way that it was discussed, but for the accuracy of the minutes, it may be okay, but I wanted some clarification on when we talk about service members with mild TBI, and it is in here a number of times, it is referred to as in present tense, as though the service member has a mild TBI.

There was another area in here where it was referred to that people with severe TBIs who improved to a state of a mild TBI, I think those are inaccurate statements. A TBI is defined on the basis as a severity at the time of the injury, and to have a mild TBI up front versus a moderate to severe TBI with good resolution to a certain new baseline, still those are two totally separate entities.

I think anytime that the reference is to the TBI, it should be to the initial event, what happened,

and how it was categorized, and there are very specific definitions that are agreed to with a number of different associations with this.

The other thing, too, I think it is more important to refer to a history of having had a TBI rather than someone presently has a TBI. They may have brain damage or brain injury from a TBI, but the TBI occurred at the time of the injury itself.

Like, for example, on page 6, I think it's the third paragraph down, it says, "A lot of people initially diagnosed as severe might recover and later have a mild TBI diagnosis." I think that is an inaccurate statement and should be changed.

By the way, also, the paragraph above that, not that I have a critique about it, but this is something that I think this committee really should look into because we have encountered this, as well, that cognitive rehab is not covered by insurance companies, and I think that is an issue that probably we need to address through this meeting.

As a matter of fact, some of the DVBIC VA centers, we have attempted to send some of our patients

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to with more moderate to severe injuries or cognitive behavioral rehab, especially those who had had a lot of frontal lobe damage, were literally sent back to us saying that we really don't have anything like that in place.

They could get all the PT and the OT that they wanted, but they didn't have anything in place for cognitive behavioral rehab.

I think also as we categorize these injuries from mild to severe, somewhere along the line, again, this is not in reference to a specific statement in here, but we should note the variability of recovery within each group, that it is not standard among -- that you can expect this much recovery among milds or moderates or severes that we should emphasize that there is a lot of variability depending on the individual themselves.

The other thing with regard to -- perhaps we could get into this tonight at the open forum meeting -- the paragraph on page 10 that refers to entire family members, one of the things that we discovered is not just the -- I think Maraquita sent out a slide show on the children of TBI victims and how it affects them.

We note that there are many children or sibs of the service member who remain at home where the service member may be from someplace in the Midwest or the far West, and they are being treated at Walter Reed.

One of the parents has to be with that individual or perhaps a spouse or whatever, whereas, the children are at home, and the focus on the kids at home I think has been somewhat overlooked, and we should probably include that among our missions.

The other thing, too, with regards on page 11, I think about the fifth bullet down, where it says which signs and symptoms are the TBI patient going to exhibit and how do those symptoms reveal themselves and when.

Again, I think we need to stress here the variability depending on the location within the brain of the lesions themselves. It may be a big difference if somebody has a left temporal contusion or whatever and has problems with language or memory versus somebody with an orbital frontal lesion that has disinhibition or loss of social tact.

Anyhow, those were just a few things that I thought I would bring up that I noted. It's not

necessarily changes that need to occur in the minutes, because they may have been discussed this way. At least I think things that we need to focus on correcting or elucidating a little more.

MS. CAMPBELL-COTLER: Thank you very much.

We do have a transcriptionist here who captured your comments and I have been taking notes, as well, as you have gone through.

I know that some of the statements that appear here are what came out of general discussion from the meeting in January. We captured them as they were presented without any filtering, so I am glad that you have made the comments that you have made, and we will make the changes to the summary notes that need to be made.

Any other comments?

MR. DODSON: I would like to echo a little bit about that, but let's not miss the point that there are sometimes when the patient will recover to a certain degree of normalcy and then years later have a spontaneous event. I was wounded in 1969. In 1980, I was in a college classroom and I woke up in a

neurosurgical ward. I had a massive -- what do you call those things -- not stroke -- seizures. That was brain operation 3 and 4.

Your comment about what was the initial diagnosis is correct, and then go into, okay, what parts of the brain were injured, what parts repaired themselves through neuroplasticity or through --

DR. FLYNN: Maybe in follow-up to that, too, and I think underscoring this was Mike's presentation at the last meeting of the movie that he showed. One of the things that I am noticing with a lot of our returning soldiers at Fort Lewis is that there is a misperception sometimes about what mild traumatic brain injury means, and when you refer to mild traumatic brain injury, many of the service members and their family members are thinking that you are diminishing the validity of the severity of their injury.

So, it becomes very important that we make sure that our families understand that mild, moderate, and severe are medical diagnoses based upon very specific criteria that are laid down by traumatic brain injury organizations and that the term "mild" is in no way

pejorative or denying of the fact that a mild traumatic brain injury by definition could affect that individual serviceman quite significantly and their family, so mild is not a subjective term that we impart to those who are injured. It's a strict medical diagnosis, and I think we need to differentiate that because a lot of soldiers think that you are demeaning the injury that they suffered.

MS. MOESSNER: I think in the civilian sector we worked very hard for many years to differentiate between initial injury severity and residuals, and that either can be mild to severe. Severe injuries sometimes result in mild residuals. Many folks with mild injuries and with severe residuals, so really differentiating between the two is not helpful.

Shall we go ahead? Do we need to formally accept those notes?

Everybody in favor of accepting the notes with the changes discussed at this moment, please indicate by aye? Do you want to say aye, raise your hand? Ayes?

[Chorus of ayes.]

MS. MOESSNER: Okay. Any objections?

[No response.]

MS. MOESSNER: Okay. The notes will be accepted with the changes.

Moving on to the next agenda item, it looks like Maraquita, perhaps you are up for review and approval of the timeline.

Review and Approval of Curriculum

Development Guidelines

MS. HOLLMAN: Going around the table is a timeline that we have been working on, and we have worked on several versions. I think since the project has started, there has been probably 11 or 12 versions which has changed from the appointment process to when meetings were going to be, and what we have done is we have narrowed that down.

We really looked at two columns, the milestones and the date, and we have tried to really pick out some key items really to focus on, and one of the things that as we know with these types of projects, that these timelines always change, so we are not saying obviously that this is cast in stone, there is a little variability.

But let me tell you the one date that does not have variability. That is the final report to Congress on the second page, and that is due to Congress on the 1st of August.

What that means for us, we basically need to back that up about a month, because we need a draft final report by the 1st of July, so that everyone can look at it, revise it, make additions, and there are going to be individuals outside the panel that are going to be reviewing it.

So, the August 1st deadline for congressional report, that we cannot move. That is something that is set in stone. The other thing we have a little bit of variability in the event that something comes up.

So, what I would like to do is just kind of give you an idea of what we have listed on the timeline and just pretty much go down some of the dates that we were thinking.

Again, this is just for organizational purposes. From our side, obviously, this is the timeline that you, as the panel, would be working with. What we have done is we have envisioned three drafts of the

curriculum and again this is only our idea, and that you, as the panel, have the final word on that.

But what we have looked at is three draft versions, which would then end in a final version, and we were looking at having that final version then by the 24th of October, which would coincide when that comes in, it would be distributed for everybody to review, and then we would have a third panel meeting.

We have selected some dates. I sent them out over the weekend and we will be looking at those tomorrow to establish the date for that third panel meeting. It would be either in late October or in the beginning of November, and our goal at that third panel meeting would be to really look at the curriculum.

It would be the last time that it would be looked at, and it would be reviewed and approved, and then we would also be looking at developing recommendations for site selection, and the summation plan as I am posting on the left.

So, we would be looking at completing that by the 14th of November. After that, there is a presentation that the curriculum would be presented to

the Defense Health Board, and if you recall, back in January, when we had that organizational meeting, we had talked about the presentation to the Defense Health Board.

So, that is another requirement. Do you want to add anything, Colonel Gibson?

COL GIBSON: We will do that the first week in December. Let me tell you why. As a subcommittee, you guys are able to meet like this, with the door closed, hash out things, do teleconferences, do all those sorts of things to get to a product as long as your product is deliberated in open session of a Federal Advisory Committee, in this case, the Defense Health Board, so the public can see your product, your Chair can explain how you got to where you are at, et cetera.

Releasing it then to the Department of Defense, which is basically what you are doing on the 31st of December, is a nice timeline for doing that.

If you were not a subcommittee of a Federal Advisory Committee, because you have non-Federal people on this group, you would have to be a Federal Advisory Committee, and you would be subject to all of the rules

and regulations of the Sunshine in Government Act, which means that you would have the public behind you right now listening to how you are going through your president, you know, what we are going to have for lunch, and whatever else you want to talk about.

This gives you lots and lots of freedom, and one thing you need to do is update the Board on your progress and deliver our final products that they can then say this looks like a great thing, and it's not a rubber stamp.

The other thing for you to know is it is your product, it is not a product of the Board's, it's a product of this subcommittee, so you don't lose ownership for all of the hard work that you have done.

So, that is the reason that we are doing this the way it is. We were able to talk the lawyers within the Department of Defense into this approach, and they touch back to make sure Congress was okay with it, but otherwise you would be everything that a Federal Advisory Committee has to have would have to be done, and I can tell you that is an onerous list of requirements.

Anyway, that's it, and I would guess during the

first week in December, we will schedule a meeting of the Board to make sure that we are covered for this.

MS. CAMPBELL-COTLER: Thanks for that explanation.

MS. HOLLMAN: The next thing that we would need to do is after the DHB meeting, it would then have to go to the Director at the -- some of us had just started -- the Center for Excellence -- we are not doing that?

COL JAFFEE: Go through it.

MS. HOLLMAN: Okay. We also are looking at pilot test sites because we think it is important that it actually go out to a certain number of sites and would actually go through the function of some pilot test sites, and those sites would be identified hopefully at that third panel meeting that you would have, and that would give us the opportunity to actually take that, move it into a pilot test range, and actually get feedback on it from individuals who would be actually looking at it and using it.

Once that would be done, we are looking probably about close to a month for that. Then, we would obviously take that feedback that we had gotten through

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the pilot test process and then roll it back into another version of curriculum, so that those additions or revisions, subtractions could be included in that particular version.

After that time period and once we would have that, that particular curriculum would need to be reviewed again and approved by the panel, and then it would be sent for distribution and duplication.

After that time period, once we would actually have it in hand, then, it goes full-fledged into the distribution mode for DoD sites, VA sites, civilian sites that you had identified during that first organizational meeting back in January.

Then, we are looking at another evaluation process while it is actually out there, so that you can go through that particular set, so there is actually a pilot test for evaluation and then there is a short period with evaluation once it all goes out.

That would pretty much take us through the month of May and then getting that data back and analyzing it pretty much by the middle of June, so that we could have that completed then by the time you would

have to have the draft report that would eventually go to Congress.

What we will do is we will research to see if there is a particular format that that congressional report needs to be in, so that we are not re-creating the wheel and getting clarification of what that needs to be in, and if there are parts that we can pre-write, I guess would be there is probably a historical component, a methodology component, processing.

Those particular parts can be written ahead of time, so that we are not pretty much having a large amount of time taken with those. As you would work on those particular parts ahead of time and have those prepared to make it easier to actually put that draft final report together that would be due the 1st of July.

I also want to draw your attention to that as part of the draft report to Congress and to the final report to Congress, there is going to be a separate section in there regarding your experiences as paneled individuals.

We really want to look at what it was like for you to sit on this particular panel, in essence, what

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were the high points, the points that could be done different, and we really want to include that.

So, as you go through this particular process from this day forward, and we really start intense work on this curriculum, kind of keep that in the back of your head, and if you are like me, you kind of keep a little separate file on your computer, you have a little notepad that you jot some things down that as you are going through this process, you want to remember that.

Kind of think about that now, so that when we come to the later parts of next year, you are not trying to remember what happened back in last year in 2008.

So, those are some of the things that we are thinking about according to the timeline. Again, I mean there is variability here. These are just some of the things that Meg and I have talked about and kicked back and forth quite a lot, and looked at several different versions of timelines, and these are milestones and dates that we thought were feasible and gave us the process that could be very beneficial with evaluation for pilot testing and then full-fledged evaluation, and also really looking at a couple of versions of the curriculum, and

moving up, and then also incorporating that final draft version would coincide with the third panel meeting, so that we are not making and asking individuals to travel again during that time period.

Also, it is pretty much fall and we are not looking at summer when we have school and when we have travel then.

MS. CAMPBELL-COTLER: One of the things that we have grappled with is the idea of getting feedback, review edit and revise. We are considering and will, based upon the kind of variety of feedback we get, a look at having a webinar with some other interactive televised video conferencing, so that there is an opportunity for folks around the table to interact without coming into Washington, but there may be issues that we really will have to hem around and discuss, and we won't know that until we get the first round of feedback from the curriculum.

So, we are prepared to have this be an interactive a process as possible and to have an ability to work out any questions or differences that may come up as we review the curriculum as a group.

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I wanted to know how you felt about that, is that something that you are okay with. One of the concerns I guess I have is whether at your sites you would have access to that technology, so all those things could be worked out.

It is understood that the curriculum as we use some shorthand language in terms of the transmittals and the approvals, it is understood that as the organization that is sponsoring or one of the groups that was administratively responsible for the curriculum, that DVBIC and the National Director of DVBIC, would be doing the transmittal of these materials to the DCOE and to the Defense Board, et cetera.

It is an ambitious timetable, and we are going to be asking all of you to be working very hard over the course of the summer, which is usually a time when people like to relax a little bit, and I wonder what your thoughts are about this ambitious timetable.

MR. WELSH: It seems like it is too long. I don't think it's aggressive enough.

MS. CAMPBELL-COTLER: Oh, okay.

MR. WELSH: It is detailed and it is thorough

and it is very precise, but as stewards of the people, I don't see how it could take two years to produce this product based on the needs of the families out there now, we should be dealing better for them, and that would require it should be that we ramp this up.

You have a dedicated staff, you have hired writers, hired experts, if that is their full-time mission, if they don't have another charter, doing some other work, maybe I am naive on this, but the research and the evidence is already done, the work is grabbing information that is already out there, and putting it into a batch that works for the military family.

I appreciate the detail, but --

MS. CAMPBELL-COTLER: Sure, I hear you. What would you recommend for the final draft, the one that the panel would approve, would you move it up a month, to the end of September?

MR. WELSH: Well, from today, 180 days it should be complete.

MS. CAMPBELL-COTLER: 180 days from today?

MR. WELSH: Or at least 180 days I would provide it to the Board for their review.

MS. CAMPBELL-COTLER: To the Defense Health Board in 180 days?

MR. WELSH: Right. And I don't know what the identifications are when we have a change in the White House, do our appointments carry over, does it overlap?

COL GIBSON: You have to be reappointed every year, but it is an administrative paperwork issue, you have a mission, deliver it, let folks like me worry about the administrative.

This date, after your third panel, when you have completed the product, and you are presenting the curricula to the Defense Health Board, just before you give it back to the Center of Excellence, that is a very important time, your quote is 18 months -- let me go back one step.

This was not in the 2008 NDAA, it was in the 2007 National Defense Authorization Act. We are behind by a year already. There was lots of problems in getting this group stood up, discovering that, oh, wait a minute, this has to be a Federal Advisory Committee made some problems.

We soldiers need this, family members need

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this, so anything you could do to wrap this up is very beneficial. That day in December basically says we have produced a product, here it is, it is not final, but here it is, DoD, test it. That is something that the Department can grab a hold of and say in another type of report to Congress say they delivered it, they are only a year behind rather than two.

MS. CAMPBELL-COTLER: And the December date is essentially 180 days from today. That is 180 days, six months, and what date is this, June 17th, so we are maybe two weeks behind with the December 31st transmittal date.

MR. DODSON: Just a comment. I echo Mike's concerns. In our work, we are working with about 230 Wounded Warriors at Walter Reed, we are picking up -- going into Bethesda and picking up about another 60 or so Navy and Marine people.

Of that, Walter Reed has over 700 inpatients and outpatients, I can't give you the exact number because I think it's sensitive, but DVBIC, what we are using for the family caregivers, because we get nonmedical caregivers, mothers, father, brothers, sisters, wives, husbands, what we are using is that

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outstanding resources that DVBIC has and their pamphlets are just missions and families, they have life after brain injury, a guide for families, life changes when a spouse or partner has a brain injury, caregiving after brain injury, a survival guide, helping dependents when a service member has a brain injury, families as caregiver, managers of care and services.

We are using those pamphlets when we interview the Wounded Warrior and their families, we use those pamphlets and give them to them, thanks to DVBICs, thank you very much.

MS. CAMPBELL-COTLER: Those are the TIP cards.

MR. DODSON: Yeah, those are the TIP cards, and, you know, there is two other categories of TIP cards, behavioral and communication issues, and that is for the patient, and return to duty and work issues, that is after you are released.

MS. CAMPBELL-COTLER: I would like to keep the discussion focused on the timeline right now in terms of what Mr. Welsh was saying and whether you think that the time isn't aggressive enough and whether there are some areas where we might move this forward.

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MS. SARMIENTO: I just have a quick concern about I think it's like the March 15th or April 1 date, just because with my experience in doing national initiatives, I go through the Government Printing Office, and I don't know if you guys do as well, but I generally have to give them about six weeks, so I think that is very aggressive.

It would be great I mean you can if you have the funding, you can print things very complete, but that is going to really upset your current budget, there is always problems in printing, always problems with graphics, so I think it would be -- I have never seen something turn around that quickly.

I would just recommend -- I know that we are trying to not squeeze it, but I would definitely think squeezing different times -- and then the other thing is in the timeline, and maybe this is just not laid out, but there is no time for actual like a launch, a promotion.

So, whether you are doing a pre-promotion of it, such as coming soon, the purchasing things are happening, you are doing your mailing lists together, getting all those sorts of things together, and I don't

know if that is just all under one general bullet, but I would also recommend integrating that into a timeline, but it is very time consuming to develop the web pages, develop the promotional material, and think of the plan, so I just have a few concerns about that.

Overall, about the general one year, we would love to get it out earlier. My experience with national initiatives, it usually takes the quickest turnaround is about 6 to 8 months, and what is when we have a lot of pre-existing material, so it is pretty tight.

MS. CAMPBELL-COTLER: So, you are coming at this except for providing us with some more time for curriculum examination, maybe having dissemination scheduled for April 20th as opposed to April 1st, giving a month?

MS. SARMIENTO: Well, it depends on how you are printing it, if you printing it at the Government Printing Office --

MS. CAMPBELL-COTLER: We are aware of that, okay, and also to insert a promotion timeline in here, recognizing that, yes, excellent idea to put these out on some of the military web sites.

MS. SARMIENTO: Town meetings, conferences whatever is coming up.

MAJ VOGT: Maybe instead of delaying that launch to April 20th, when we are going through all these drafts, first, second, third draft reviews, we might not need a month in between each of you, if we could speed that up, and that would give us time to do the print off, and keep that on schedule.

MS. SARMIENTO: Adjust it, so it is more reasonable.

MAJ VOGT: So that there is more time to do the --

MS. CAMPBELL-COTLER: What do you think is a reasonable amount of time for the review process when you receive a curriculum, how much time do you, as individuals, feel you need to provide feedback to us, and then we need to be deciding then based on the feedback, whether we need to have an interactive event or whether we can communicate one on one, what do you think is realistic?

We just didn't know based on the mean this summer, and your schedules, what was an appropriate time

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frame.

MAJ VOGT: I think probably that first one needs to be a longer period, but then the second and third review I think we can kind of shorten up, because by then we will have all gone through it, so maybe two weeks between --

MS. CAMPBELL-COTLER: Is two weeks a better --

MAJ VOGT: Between the second and third?

MS. CAMPBELL-COTLER: -- does everyone feel more comfortable with that?

DR. PRIES: Just a comment that with a group this large, we know that not everybody would be able to be on every call, so if you can't be on a call, that it is incumbent upon you to provide your feedback in a timely manner, in some other manner, but the process is going forward. Whether I can be on or not, it is going ahead.

MS. CAMPBELL-COTLER: Yes, thank you very much. The first round we are hoping will be comments in writing and then we would move to a phone call perhaps to clarify conflicting feedback that we are getting.

MAJ VOGT: Yes.

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MS. CAMPBELL-COTLER: So, would everyone be comfortable then with a two-week turnaround for the second draft and the third draft? Okay, and that will move the process up further.

Linda, you have been trying to say something, I am sorry.

MS. ROHRET: I am really concerned about the timeline. Sometimes the review process, I wasn't going to comment on that, but the review process doesn't take the amount of time that we think it will. Sometimes it takes a little longer. I do agree with you about all of what you had said.

I am especially concerned, though, about the pilot phase. I was thinking about focus groups and the pilot phase is especially important to make sure that it does work for all the folks that we are trying to reach.

It isn't especially long at all, and once it is piloted and we make the changes, then, it should be pilot tested again to make sure it was changed in the way that the folks had needed it to be, so there should be another pilot study in there.

MS. SARMIENTO: Perhaps another iterative test,

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and so you do one test or two tests, depending on what you have the clearance for, and then make changes, and then have your next group make changes in between, and that has been better with short timelines, but ideally, you would do all six to eight groups and change over.

MS. CAMPBELL-COTLER: Yes, I am concerned about the timelines in that regard. We hope, we certainly want to have the sites pre-selected and the folks at the sites prepared to go as soon as the curriculum is prepared, so that these focus groups would take place, you know, within 24 hours or 48 hours of receiving the curriculum.

But as we are adjusting this process, let's take a look at that. We have gained a lot of time in terms of the review process, almost a month.

MS. ROHRET: You are going to have such a variety of caregivers.

MS. CAMPBELL-COTLER: That piece also goes to our next discussion on target audience in terms of who in the audience that we want to pilot this curriculum on, and that's another discussion for later this morning.

Pat?

MS. COLLINS: Will pilots require IRB approval?

MS. CAMPBELL-COTLER: This is a curriculum. I asked that question, and because it is not research -- please comment.

MS. SARMIENTO: I think because it is going to be with the service members, correct? I think Federal employees do not need to get --

DR. PRIES: It's caregivers.

COL JAFFEE: This is an educational initiative, so whenever we produce products, those are not necessarily IRB types of issues, and if we wanted to do a study to see how effective this product was, and develop parameters to study that, that would be a study that would be research, that would require IRB approval, but just actually producing an educational product or initiative itself doesn't necessarily require IRB.

MS. CAMPBELL-COTLER: And evaluation of the product rather than the effectiveness of the product for the caregiver who has received it, that's the difference there, we are evaluating the educational product.

I think you were first and then -- I am sorry, I am having trouble reading names.

DR. PRIES: It's Rose Mary. The other thing

that I think we need to build in is we assume that everybody is equally skilled at running a focus group, and we may need to build in a little bit of time for training the folks who are going to run our focus groups, because it's not -- yeah, you need training to do it effectively.

DR. BENEDICT: Almost to build a curriculum so they can follow it.

DR. PRIES: Exactly, and maybe build in a conference call, so that all these focus group leaders are singing out of the same song book.

DR. BENEDICT: Just to speak to the issue of the IRB approval -- running a pilot program now of a web-based interactive tool, a family care map, and we sort of tackled that issue initially about the IRB approval and whether or not we needed that, and at least the four centers that are doing this now, all their IRB boards declared pretty much that it was a quality improvement tool and that they didn't need to go ahead and seek our approval, and signed off on that, so I think it was kind of in the same ballpark.

COL GIBSON: This is consistent with the idea

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of it not being research, so it all fits together.

MS. CAMPBELL-COTLER: Great.

DR. PRIES: And no surveys, so we don't have to involve OMB.

MS. CAMPBELL-COTLER: So, what I have heard is that we want to -- we are going to leave the review time frame the same for the first draft, but we are going to move up the review and edit process for the second and third draft by providing only two weeks for the turnaround on that, which will, of course, move up the final draft curriculum submitted probably to the end of September.

So, we may be able to move the whole process forward more providing sometimes for promotion and may even for a second pilot when that is determined.

The other piece of that, we will be contracting for the evaluation tool and the evaluation process, and so depending upon how we do that, they may, in fact, we will build into the contract having some training for the focus group leaders at the pilot site, so that is uniformity in delivery and that we meet those kind of criteria.

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With those changes, are we comfortable with the timeline? Yes?

DR. FLYNN: I was just going to say I think most of us that deal with the government realize that you have to build in a fudge factor or flexibility for time.

One of the things when you have a timeline that is set, that you feel is more than reasonable, you can always expedite matters and work faster within that timeline, but if you set an expectation for yourself that is constrictive, and you say you want to be done by this date, and then you are going to be held to that expectation, and if anything goes wrong, you know, you are going to be cooked.

So, I think we need to leave this that liberal flexibility in the schedule and then if we find ourselves working faster, so be it, but I don't think we want to restrict ourselves too much.

MS. CAMPBELL-COTLER: Are you saying that the two-week turnaround for the second and third --

DR. FLYNN: No, I think the two-week turnaround looks fine. I am looking at the overall schedule, and just a question, Meg, is this timeline for completion, is

this submitted, as it is right now, up to anybody in Congress who will be receiving it?

MS. CAMPBELL-COTLER: No, this is our working document.

DR. FLYNN: So, nobody up there knows when it is that we are putting expectations on ourselves for?

MS. CAMPBELL-COTLER: Yes, but we do have the expectation, an external expectation, that this will be completed by August 1, so that really is a timeline date that is public and that one will be held to.

COL GIBSON: The only thing Congress or anybody else will see will be redacted minutes on Wednesday.

MS. CAMPBELL-COTLER: Any other questions, comments?

[No response.]

MS. CAMPBELL-COTLER: So, we will make the changes that you all have recommended in this timeline, and get it back out to you in follow-up of today's meeting.

MS. MOESSNER: Great.

MS. CAMPBELL-COTLER: Thank you.

MS. MOESSNER: Thank you. You have obviously

put a lot of work into it and multiple revisions of the timeline. Thank you for giving us something to respond to.

It looks like there is one more discussion before the morning break, and Colonel Jaffee.

MS. CAMPBELL-COTLER: And Colonel Gibson on the Defense Health Board meeting the 8th of April this year.

Defense Health Board Curriculum Feedback

COL JAFFEE: So, being an official subpanel of the Defense Health Board, whenever the formal Defense Health Board Committee meets, each of these subpanels have to give a status report, an updated report, and so they held a meeting.

It was actually held in Tacoma, Washington. It was on the 23rd of April, and by that point in time, everyone on this panel was officially appointed by the White House and this was on the books as an official panel, and so I had the opportunity to introduce the formal DHB for the first time to the concept of what this panel was about, and the way those presentations are done to the members of the Defense Health Board is it is done with a PowerPoint presentation.

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Those meetings are open, so they are matters of public record. Anyone who would choose or who would like could actually go to the web and look up the Defense Health Board and look at all the presentations that were given during that two-day meeting.

If you are interested we will provide copies of the PowerPoint presentation for you, but basically, what that briefing was, it sort of brought the members of the panel up to date on the legislation which created this panel, about the process that we had gone through of creating the members of the panel, putting it together, describing the purposes and the objectives of the panel.

We talked about and summarized the aspects from the January meeting. We talked about how we organized that meeting with the breakout work groups and some of the functions and objectives that the work groups were dealing with.

We talked about some of the expected outcomes and goals for the panel and the curricula. We did mention the bottom timeline, we didn't get into any of the other aspects. We just talked about when the other aspect was up.

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One of the reasons why that is also important for this panel is just to clarify the way, as Colonel Gibson mentioned earlier, the way this panel was created, was it's a time-limited panel, if you will.

So, once the work is done, that curriculum is developed, the panel will expire for lack of a better term, and as Colonel Gibson mentioned, because of that, we wanted to assure success, and that was also discussed in Tacoma, and it has also been discussed with the TBI panel, who is willing to take on that responsibility for making sure that the grade products and work of this panel does get followed up upon and is properly implemented and things like that, and I imagine that some members of the panel may be called upon for their continuing expertise to consult to these panels as we go forward.

So, the way the Defense Health Board works is once you give that type of briefing, then, they sort of go around and they give each of the members of the panel a chance to react and make comments and suggestions and feedback.

So, we had the opportunity to collect that

feedback, which is now incumbent upon us to then convey to all of you here, and I will let Colonel Gibson sort of summarize that.

COL GIBSON: Well, basically, the Board members listened to these briefings, and they welcomed the process, they thought the process that you guys were going through was appropriate, should yield a good product, the fact that you have the focus groups and an evaluation of this curricula built into the system was very much welcomed by the Board.

They are expecting periodic updates as this process goes along, expecting the -- although we didn't talk about exactly which meeting you would present your draft curricula at -- they certainly were not only amenable, but wanted to do that, and as Mike mentioned, and you all know, a curricula like this is iterative.

It is never done, it is never complete, so they understood that. I believe Congress really actually understands that, too, although if you look at the legislation it said deliver this, done, got a ribbon on it, done, this is the reason why the Traumatic Brain Injury External Advisory Subcommittee would be asked

continuing -- there is an issue of if you use the word "oversight," that implies something that only the President can do.

He can put together a commission, et cetera, to provide oversight to the government, but what we can do is use the word "update."

I talked to two of the Board members who would be involved in the TBI Subcommittee, and they both were talking about we probably need to appoint one or two of the folks from this panel to the TBI External Advisory Subcommittee in the future once this product is done.

So, look forward to a couple of you might go on and on and on with this issue, and have an opportunity to provide expertise on the issue of curriculum updates.

They understood the need for this, absolutely understood the need. We already know that things are going on within the Department to provide advice, recommendations, training to family caregivers, but the product that you produce is going to be an important part, and they truly understood that.

With that, I think that is about all. Did you pick up anything else from that, from the discussion,

besides those points?

COL JAFFEE: There were some specific suggestions, so I will just share some of them. Some of the comments that were made, I think we are already doing, but I will just for the sake of completeness kind of summarize a few of the comments, one of which was there was the expressed hope to, as part of this, consider establishing a family network that would be web based.

In thinking about the people who touch families and caregivers, the point was made was whether we wanted to establish a faith network assuring that clergy, both civilian and military might be involved, which I thought was a very valuable contribution.

There was the expression or desire to make sure that we are providing the perspectives of patients themselves, which I think the committee has made plans to do so.

From an educational perspective, those who are familiar with curriculums wanted to suggest to consider organizing around competencies and support more so than the curricula itself, focusing on a competency based as

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opposed to content based as one consideration or element to consider when designing a curriculum, assure that we are incorporating consideration of comorbidities, both psychological and physical, which I believe the members are very sensitive to, including the needs of civilian caregivers who may not be a family member as well as defining the family given modern variations.

I know a lot of discussion started in January. There has been some materials, and we are going to be discussing them more.

So, I was assured hearing a lot of those comments that the panel is already kind of on track with a lot of the input that they had, and one other sort of technological means that was introduced for us getting feedback either on the review stage or as we developed as including the use of webinars.

But again, the big idea, as I said, those were specific suggestions. I thought they were suggestions of support with the overall idea being enthusiasm and very much support for this mission.

MR. WELSH: What was the last one you mentioned, web?

COL JAFFEE: Webinars. It is just a form of reaching people who may not respond to written surveys, but they might respond to e-mail and web things. It is a way of reaching out and touching more people to get more direct feedback.

MS. CAMPBELL-COTLER: Any other comments or questions?

COL JAFFEE: Or DHB member.

REV. CERTAIN: DHB member certainly. I am sure an oddball on that panel, because I am their clergyman, and not a scientist, and as Dr Jaffee says, my concern was that, among other things, that we would do well to at least point in the direction of what else is going on in the community.

Congress has narrowly defined the role of this panel, but the civilian population doesn't care about Congress' timelines or about this panel. They are doing it anyway. So, networking or at least acknowledging the sort of substantially the work of family support out in the community including faith communities, it is community-based support programs, training for TBI the larger network of brain injury work that is included in

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shaking baby and car wrecks and everything else that results in head injuries, which is going to be important for the sustainability of caring for our veterans long after the current conflicts are over.

I don't even know, I have got a group trying to get a handle on just what is going on in north Georgia, and getting the web-based information and networking going as a resource to our Guard and Reserve in here.

But there is a lot of local initiative we are discovering, a tremendous amount dealing with veterans affairs, as well as the support of their families, and Congress needs to understand, I think, first of all, that the DoD has a role to play, but it is not the role, and that this a nationwide community issue, and we need to call in the country to make the necessary sacrifices to care for our troops beyond what DoD, VA, are capable and able to do because of funding, location and everything else.

The rural issues that permeate your last discussion comes to mind, and how we are going to support people in the long haul.

I would like to see the panel at least commit,

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in writing, all the community-based initiatives as well as maybe suggest that that is an appropriate community sacrifice in time of conflict to pick up where the Army, the Veterans Administration necessarily leave off, and to recognize as politically unacceptable as it seems to be today, the faith communities still affect and care for an enormous proportion of the population.

So, one of the test sites you might want to include some faith-based service agency to test the curriculum in the rural area or the area away from military center, VA center where veterans, particularly in regard to Reserve, are located to see how it works out there.

MS. CAMPBELL-COTLER: I just wanted to ask you whether you were aware of any initiatives from among the denominations that we should be aware of, you know, are the Baptists, the Catholics, the Jewish congregation, at a national level, are they looking at this and is there some way we should be interacting with them around the dissemination of the curriculum.

REV. CERTAIN: I am an Episcopalian, which makes me sort of an outcast in the world, a tiny, little

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denomination of Christians, but we have regular training programs and curricula for families and caregivers, a variety of things, everything from hospice, palliative care, supportive when somebody has gone home for that, the support of those families who are doing the direct --

MS. CAMPBELL-COTLER: Stephen Ministry.

REV. CERTAIN: Stephen Ministry is interdenominational. We have a Congregational nurse program, and we train -- we are networking and training people in the North Georgia area, so they are not focused on TBI care, but they are focused on taking care of the family caregivers, everything from child support for the under 18 caregiver, to the spouses, brothers, siblings, parents and others in the household who are doing that work.

So, there are some ways I think to get in touch. Probably the best contact is actually in Savannah, Georgia, is the Director of -- not just the acronyms -- for the umbrella organization that endorses chaplains through the military. I will have to look back in my notes to get that acronym, but that would be the most likely first point of contact to get into all the

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denominations at least and faith groups that provide chaplains to Armed Forces.

MS. CAMPBELL-COTLER: Jane, you have been trying to say something.

CAPT HEPPEL: I just wanted to mention that when General Sutton, who is head of the Defense Center of Excellence, TBI, and traumatic psychological trauma, and not the global center, when she came to speak at our service members with TBI summit in April, I think that was a real acknowledgment that there is a civilian network across the States and Territories that has been in operation to serve people with TBI since 1997, and for the last three years one of their two priorities has been to outreach, to service members and their families. They have been doing this, and they continue to do this, and there other federal initiatives.

You know, sometimes I go to so many meetings and I hear about all of these initiatives that are going on, and I think in stovepipes and not really aware of each other.

Recently, I know there has been developed in HHS, Department of Health and Human Services and

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Department of Veterans Affairs Task Force, and I recently went to one of their meetings in which the role of the Substance Abuse and Mental Health Services Administration was discussed.

We know that there are not enough mental health care providers to take care of the active duty members, let alone the dependents who need care, the caregivers being a big part of that, and I just would be remiss if I didn't mention that right now, at Bethesda Naval and at Walter Reed, the only people being served are active duty service members, so when you see that exhausted looking mother of a service member pushing her son around in a wheelchair, we need to recognize that when she is close to the breaking point and needs mental health services, she can't get them.

Now, I understand from what I read this morning that there is support at VA centers, but if this is the policy at Walter Reed and Bethesda where we know we are having a large number of people treated, I think from our discussion last time, one of the things that we talked about with respect to caregivers was avoiding burnout and getting help when you need it.

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We can write all the curricula we want, but if they can't get the help they need in a timely fashion, that is a huge concern to me.

MS. CAMPBELL-COTLER: That is a good point.

Comments on the Defense Health Board recommendations? Have we finished the comments on --

MS. ROCCHIO: Well, I had a comment to follow up on the faith based. We have a National Caregivers Conference sponsored by the Brain Injury Association in Dallas, and I was pleased that there were two chaplains from the VA system that attended that meeting.

There is also a wonderful booklet designed for ministers, priests, anyone in the faith-based community.

It was originally done by the New Jersey Brain Injury Association. It is called, "When the Call Comes.

It's a wonderful book. It's a small booklet about this size that is designed to be handed to -- it's to train the ministers to work with the family, exactly what they are talking about, and it is specific to brain injury. It is called, "When the Call Comes."

It is still available through -- I don't know, Janie, if it is in the MERCEF [ph] catalog or not.

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MS. HEPPEL: I don't know, but I can look.

MS. ROCCHIO: Yes, I don't know. I haven't checked for it there, but through the New Jersey Brain Injury Association, it is I think still available.

MS. CAMPBELL-COTLER: Rose Mary.

DR. PRIES: Coming from a public health model, I think one of the things that may be very helpful given our current discussion, is that perhaps a side bar to what we are doing, because of the need for community collaboration, that we need to offer folks some suggestions or guidance about how to do that.

I mean we kind of assume that people in the community know how to get together, know how to network, know how to facilitate, and I am not necessarily sure that that is true. I think what we find, that people are operating perhaps in stovepipe.

So, maybe just a little bit on community organization, the skills that one needs if you are out in the community to network, collaborate, get together and provide better services

MS. CAMPBELL-COTLER: Thank you.

COL JAFFEE: Just a couple of comments. The

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name of this actual program is The Family Caregiver program, and the curriculum is an important product, but it's not the end-all, be-all.

What I am trying to say by that is that as members of the panel, you can make recommendations about these other aspects of implementation, and whether that can be addressed in the time that we have on this panel is one thing, but if there are standing recommendations that you make, and say we recommend that DoD look into or evaluate or develop, those recommendations would last even beyond the span of the panel if need be, such as one thing to keep in mind especially as we are thinking about implementing.

There are a number of programs being implemented trying to tie together these community resources. It is following the term -- and Gretchen can keep me honest -- of care coordination, and the VA has stood up the federal care coordinator system, the DoD, DVBIC has sort of one focused on TBI that they are working in synergy, and it strikes me that it might be of value at the next meeting to have some briefings on it.

We heard a little bit about the VA's program in

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January from some of the folks in Dr. Davis's office who had helped develop that, but that is something that we need to keep in mind, one, for a couple reasons, but I think it would be very helpful to learn about what it is they are doing.

I think it would be even more helpful for them to hear the perspective of the panel on how best to optimize those programs, and another reason is I think that would be a valuable network to tap into and we can talk about distribution and implementation of what we develop tapping into these resources which are there rather than create our own.

DR. FLYNN: Meg, it seemed that this is such an important topic, and the Defense Health Board felt that it is, this faith-based, community-based initiative, I wonder how many civilian religious leaders are provided access to military facilities because there is a security to get by on post, and if service members are from the local area and they have a priest, a minister, or a rabbi in the community that they work with, that they have close association with, how do those religious leaders get on post, and if we are looking at this as such an

important part of the recovery process for our service members, we need to figure out a way to get them on post if they can.

REV. CERTAIN: With the Privacy Act, we have a hard enough time getting them to the local hospital, quite frankly, and finding people that are in our congregation.

So, getting on the post for me is easy, I have got an ID card, but for others it takes a pretty active -- first of all, getting the awareness of clergy that they are needed, wanted, and encouraged to be interacting with the troops is one issue, and for commanders to, in all of the squeaky wheel stuff that they are dealing with on a daily basis for commanders and first sergeants to take the initiative is difficult.

So, I am not sure there is a really clear, quick answer on that, but that is one of those awareness issues that I think we might want to point to.

COL GIBSON: Maybe some of our colleagues from the services can comment on it, but it has been my experience -- and keep in mind I have been inside the beltway now for about five years, so my reflection of

reality in the rest of the Air Force at least may not be substantive anymore.

But that given, every base that I was ever assigned to, the clergy on base, the chaplains networked real well with the rest of the community because the bulk of the population on the base lived in the community, so therefore, they were locked in pretty well, and the way that you got -- and we used to have guest ministers that would give sermons on base -- that is the way to get them through the gate and set up those sort of things.

The chaplains on the bases have been successful at that.

REV. CERTAIN: There is still a lot of IMA Reserve/Guard chaplains out in civilian congregations in nearby installations. They have pretty ready access. It is the non-military associating clergy that unfortunately sometimes have been even hostile to the military operations and subsequently hostile to the military members.

That is part of the real burn in my saddle with my colleagues to get them to see that there is a human and spiritual need that they need to be helping fulfill

without imposing some kind of political agenda.

That is part of the reluctance I think on the commander's part.

CDR MILLER: Please, also don't lose sight of what the services are doing even after the service member is out, in particular, the Wounded Warrior veterans with the Marine Corps has an outreach program that is, you know, I don't think any of the services can match yet.

We are going out and every month contacting people and families and making sure that the families are supported and that program drives all the way down to the Marine for Life program, which, you know, says that you are a marine, you are a marine for life, and that they have links that drive all the way down to the small community like we were talking about earlier, so that we don't lose track of some of those things that are going on with the families.

If there is resources that we need to get to those families, the Marine Corps is assisting in getting those resources to the families to help support them.

So our services haven't totally abandoned these patients and sometimes it seems like the perception is

that, you know, once a service member is separated that they are separated and that we have abandoned them.

That is really not true in particular for the Marine Corps.

MS. CAMPBELL-COTLER: Sounds like a model program.

Are there any other comments related to the Defense Health Board meeting, because we have about 10 minutes before we break, and I was wondering if we might be able to move to any administrative business.

COL GIBSON: I think we are good to go. I just need to talk to one person off line.

MS. CAMPBELL-COTLER: I don't know if they are refreshing things for break. Maraquita, do you know?

MS. HOLLMAN: Yes, it's already set.

MS. CAMPBELL-COTLER: Okay. Why don't we then break 10 minutes early, so that we can start fresh with the family caregiver definition. It's 10 of 10:00 now, so why don't we reconvene at about 5 after 10:00 or so.

Thank you.

[Break.]

Approval of Definition of Family Caregiver

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MS. MOESSNER: If everybody is ready to get started, we are going to go ahead and launch into the discussion about the definition of family caregiver, which will drive the rest of our meeting.

It looks like we have set aside about a half-hour to come to agreement on the definition. In your packet is a handout of some of the definitions we discussed the last time. There are also some additional definitions for consideration either submitted tests or found by Maraquita in her doing a little bit of research on the matter.

It looks like this is important, but it is something we need to decide on in relatively short order, so we can keep the day moving.

I think Meg will be leading us through a discussion on selecting and finalizing and on voting on a definition.

MS. CAMPBELL-COTLER: Yes.

MS. MOESSNER: So, please.

MS. CAMPBELL-COTLER: Thank you very much.

Of course, the core of the mission is to determine our target population and certainly the

definition of family caregiver is a critical one for our work. I know that there was a lot of discussion about this at the January meeting and that you have received and you are reviewing some of the various definitions that were put forward at that meeting.

I would like to bring to your attention the definition of family caregiver created by the National Alliance for Caregivers for your consideration. I wondered if you might take a moment and read through that and perhaps we could begin there, commenting on what we like and what we don't like and begin to kind of create and sort out a family caregiver definition that we like as a group for our purposes.

MS. MOESSNER: And correct me if I am wrong, we really need to start with one of the definitions that is here and maybe tweak it a little bit, but we are not starting from scratch.

MS. CAMPBELL-COTLER: Right. I think we shouldn't be starting from scratch. I would like to begin with something that the National Alliance has developed. I guess I should ask for your comment on that, is that an okay place to start, or would you prefer

that we go back?

I think the draft language that came forward from the January meeting is just not as crisp and clear as the National Alliance definition, but the National Alliance definition is not necessarily perfect for our purposes either, so it's a compromise in my mind and if there are no objections, we will move forward with just working from this one and tweaking it to meet our needs.

Any objection?

MR. WELSH: I think I got lost there. You were talking about the one at the top here, the National Alliance?

MS. CAMPBELL-COTLER: No, I am talking about the one at the bottom actually, the National Alliance for Caregiving. Let me just read it out loud if I might.

Family caregiver is comprised of a person who cares for relatives and loved ones, such as a special friend, neighbor, support group. In either instance, the term family caregiver refers to a non-professional who provides unpaid care for others in the home.

Yes.

DR. PRIES: Just a question. Does care mean in

this context physical care or do we need to also add the term care and support, because I think it is that emotional psychological support which is sometimes a really critical factor?

MS. CAMPBELL-COTLER: I think that is correct, that we are talking about support that the caregiver is providing, not just physical care, no.

MS. ROCCHIO: I think it can't be limited to unpaid care, because in order to be here I have to pay someone to assume the responsibilities I have for my son.

MS. CAMPBELL-COTLER: Would a family caregiver be someone who is considered -- and maybe nonprofessional isn't a good term, maybe we should say not a health care professional --

DR. CHURCH: I don't --

MS. CAMPBELL-COTLER: We will eliminate the last line from this definition.

MS. ROCCHIO: I personally like the original one formed after 9/10, any family member or support group and a person who is relied upon by the service member or veteran with TBI, and is responsible for -- and then skipping down to the second alternative language -- who

assumes the primary responsibility for providing the needed level of care and overall well-being for that service member or veteran.

MS. CAMPBELL-COTLER: Did everyone hear Carolyn's recommendation?

MR. WELSH: That speaks more to a military family, the TBI acronym. It really speaks to the TBI.

MS. ROCCHIO: It does refer to the service member or veteran, but it applies to anyone I mean.

DR. FLYNN: But isn't that what our tasking is?

MS. ROCCHIO: Yes.

DR. FLYNN: So we do need to be somewhat specific in terms of it, TBI being the major reason why the caregiver is the center of our focus.

MS. CAMPBELL-COTLER: Carolyn, would you re-read that for us?

MS. ROCCHIO: Any family member or support group and a person who is relied upon by the service member or veteran with TBI, and who assumes the primary responsibility for providing the needed level or direct care and overall well-being for that service member or veteran.

MS. CAMPBELL-COTLER: Do we mean of direct care or "or" direct care?

MS. ROCCHIO: Needed level of care.

MS. COLLINS: A little earlier somebody mentioned shaken baby syndrome, and in that case it is probably not the veteran. I mean it's just a little point.

MS. CAMPBELL-COTLER: We are kind of referring to service member or veteran of TBI, right?

MS. COLLINS: Right. I didn't know if we -- I am not suggesting we shouldn't put that.

MS. CAMPBELL-COTLER: I think for the purposes of our curricula. What do the others think, should it be expanded it or should we limit it to the language we have here?

DR. CHURCH: No.

MS. CAMPBELL-COTLER: Cheryl, you are happy with the language?

DR. CHURCH: I am happy.

MR. WELSH: They hashed it out very good in January.

MS. ROHRET: We got it out of our system.

MS. CAMPBELL-COTLER: In all frankness, it was hard for me to see that with all the different alternative languages that were proposed. I had a hard time working through that myself, so that is why I moved directly to a more complete definition for us to start with, but this is fantastic.

MS. ROCCHIO: Well, Meg, should we add that this person can either be paid or unpaid, either volunteer or paid staff, because like if you are lucky enough to have any kind of respite, you are going to have to pay for care.

MS. CAMPBELL-COTLER: But that would not be -- that respite provider is now considered a family caregiver.

MS. MOESSNER: There are programs where families are paid to provide care, some of the Medicaid programs, I forget the other term, but where Medicaid programs are, in fact, allowing family members to be paid for the care that they are providing. Maybe we should just be silent on that.

MS. CAMPBELL-COTLER: Okay.

So, our definition for family caregiver is any

family member or support person or persons who are relied on by the service member or veteran with TBI and who assumed the primary responsibility for providing the needed level of care and overall well-being for that service member or veteran.

DR. CHURCH: Do we need another word in front of "overall," like ensuring the overall well-being or is providing? I think that might make a little better --

MS. MOESSNER: Yes, right. That sounds more direct, hands-on.

DR. FLYNN: I think TBI should be spelled out, too.

MS. CAMPBELL-COTLER: I agree.

DR. CHURCH: And should it not be our versus is since we have persons?

MS. CAMPBELL-COTLER: That's right, it should be are.

DR. BENEDICT: And maybe it should read who assumes the primary responsibility for providing for the needed level of care and overall well-being.

MS. CAMPBELL-COTLER: Would you repeat that?

DR. BENEDICT: I was just thinking of "for"

after "providing."

MS. CAMPBELL-COTLER: Any family member or support person or persons who are relied on by the service member or veteran with traumatic brain injury -- and then what?

DR. BENEDICT: -- who assumes the primary responsibility for providing for the needed level of care and overall well-being for that service member or veteran.

MS. MOESSNER: And down here there was a comment to change providing to ensuring to make it a little more broad. So they were responsible for ensuring the needed -- does that?

MS. CAMPBELL-COTLER: So, after "traumatic brain injury," we would say, "and who are responsible for providing the needed level of care and ensuring overall well-being for that service member of veteran"?

CAPT HEPPEL: Are we creating this definition for the end user like the person who is going to pick up the curriculum to help them, or are we providing it for the Defense Health Board, and would it be different?

MS. CAMPBELL-COTLER: Well, that's a good

question. My thought is that we are creating it to guide us in terms of what we are doing here in terms of what this curriculum is about, is it family care for this curriculum or families caring for persons who sustain a traumatic brain injury in military service.

I looked at this as a working definition for this group to be our guide, but what do you all think?

MR. WELSH: I think it should be for the user, the end user.

MS. CAMPBELL-COTLER: Uh-huh.

MR. WELSH: Because it's such a broad based group of users, we need -- I was thinking about keeping it simple, targeted for the intended audience. You know, it is for the families to use, not a trial lawyer.

MS. CAMPBELL-COTLER: Right. So do you feel that the definition we are working with now is too complex?

MR. WELSH: I thought Carolyn had it pretty understandable, and it started to get complex again.

MS. CAMPBELL-COTLER: We are spending too much time wordsmithing and what Carolyn proposed is to the point, simple, understandable.

MS. MOESSNER: I think Cheryl's comment about ensuring was -- and correct me if I am wrong -- but so any family member or support person or persons relied upon by the service member or veteran with TBI who assumes the primary responsibility for ensuring the needed level of care and overall well-being for that service member or veteran.

MS. CAMPBELL-COTLER: Right.

MS. MOESSNER: So, it wasn't adding ensuring below, you know, in front of overall down the road a little bit, it was replacing providing with ensuring, so I don't know how that sounds, but I think that sort of maintains the integrity of your original suggestion, Carolyn, and it is just a substitution.

MS. ROCCHIO: Right.

MS. CAMPBELL-COTLER: Would you like to read that one more time?

MS. MOESSNER: Sure. Any family member or support person or persons --

MS. CAMPBELL-COTLER: You might want to just take it very slow, so we can be sure we have got it written down.

MS. MOESSNER: Please, certainly.

Any family member or support person or persons who are relied upon by the service member or veteran with traumatic brain injury who assumes primary responsibility for ensuring the needed level of care and overall well-being for that service member or veteran.

MS. CHIASSON: I missed after "ensuring."

MS. MOESSNER: -- for ensuring the needed level of care and overall well-being --

MS. CAMPBELL-COTLER: Of.

MS. MOESSNER: -- of that service member or veteran.

MS. COLLINS: I suggest you say relied upon. get out the --

MS. CAMPBELL-COTLER: At the top, "persons relied upon."

MS. MOESSNER: I agree. Just get rid of "who are."

MS. CAMPBELL-COTLER: Keep "relied upon" in there, but get rid of the "who are."

MR. WELSH: Is there any reason why we need to keep those brackets?

MS. CAMPBELL-COTLER: No.

What I like about this definition is the ensuring the needed level of care and overall well-being, so that it implies that the family caregiver doesn't have to be the person who does it all, that they are overseeing the delivery of the care themselves, by themselves, or through hopefully an array of helpers, paid or unpaid.

Can we take a vote on this?

MS. MOESSNER: Yes. Any further comments?

[No response.]

MS. MOESSNER: So, as it is written, again, we will fill in the abbreviations and acronyms, No further discussion. Would people like to vote, and if you are in agreement with the definition as printed on the board, please indicate by saying aye.

[Chorus of ayes.]

MS. MOESSNER: Anyone in opposition?

[No response.]

MS. CAMPBELL-COTLER: Any abstentions?

MS. MOESSNER: Any abstentions?

[No response.]

MS. MOESSNER: Great. So moved.

Target Audience for Curriculum Discussion

MS. CAMPBELL-COTLER: The next item on the agenda is the target audience for the curriculum discussion. I would like to frame the discussion by having you think about the evaluation process.

We are going to have to do focus groups and the two pilot in order to evaluate whatever we produce. Therefore, the curriculum needs to have the target audience, how will we draw individuals to the focus group if we don't know to whom the curriculum is directed and what we hope to convey to the members of the focus group.

So, I know that in the past discussion, there was a real interest in the curriculum covering everything from mild through severe and penetrating, and I think that certainly we need to have information in the curriculum pertinent to all those groups, but who do we want to target, and on what point of their caregiving journey do we want the curriculum to be made available to an individual.

I may be totally off base here, so that is for the discussion that follows, but I just thought that we

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won't be able to evaluate this curricula if we don't have a clear vision for who we want to reach.

So your thoughts.

MS. COLLINS: Parents of veterans, active duty veterans with TBI.

MS. CAMPBELL-COTLER: Parents did you say?

MS. COLLINS: Yes. Parents, spouses, siblings, girlfriends or partners, boyfriends.

MS. CAMPBELL-COTLER: That is a component of the target audience, but then we have a very long process. You have the acute phase, you have the rehabilitation phase, you have the point at which you may feel that progress has stopped or that progress is definitely slowing down, that if the family caregiver is recognizing that this may be -- that these disabilities may be life long.

MAJ VOGT: I don't want to make this too daunting, but I don't think we can exclude any of them, because people are going to be coming into this process, you know, at all different stages, and, you know, acute, or recovery, or, you know, I mean it's an ever changing disease.

I think that is one of the things we have to keep in mind is that whatever we provide has to be able to be modular, that we talked about, being able to take pieces as you need them at that time as appropriate.

MS. CAMPBELL-COTLER: So, we wouldn't be evaluating the whole curriculum then we would be evaluating the modules that are presented that were pertinent to the characteristics of the group that were recruited to participate.

MAJ VOGT: Right, but even if you are going to, say, if you say okay, I am going to send this, you know, try this, the pilot study at, I don't know, like Elmendorf Air Force Base, you are going to have some with moderate disability, some with mild disability, some with severe disability, so even within that one base that you bring it to, you can't get a focused population, you know. I don't know if I am saying this right.

MS. MOESSNER: I think you are right, you will be able to grab people who are acute and more chronic and mild, all the way through severe, and I think you could take a snapshot of any of our facilities or centers and, you know, everybody is there.

MS. SARMIENTO: You want to keep it broad, as they are mentioning, but then for the evaluation, the objective would be different. The objective for someone or the curriculum module for a mild versus a severe would have different sort of objectives from what the caregiver, you know, so that is really what you are evaluating, the content, what we want to get across.

DR. CHURCH: I am thinking for a lifetime about -- with the structure of it being kind of specific areas that we are talking about rather than an audience, things focused on behavioral areas or functional areas or whatever the area was, and then the person who needs information could come to that specific content rather than gearing it toward a parent, because there are going to be common themes running throughout those specific areas for everyone that is a caregiver for the individual. That might help us group it a little more.

CDR MILLER: I think you also have to take into consideration comorbid diagnosis as well, and that seems to be something that, you know, if you are a traumatic brain injury plus the burn patient, plus an amputee, you have many more things that you have to deal with, as

well.

MS. CAMPBELL-COTLER: The family caregiver does.

CDR MILLER: Yes.

DR. BENEDICT: Just a comment. I just want to reiterate that we have one month built in there to ask the people who are actually designing -- what they think about, I mean I am concerned that we have all the best ideas in the world and we did a very small and medium-sized study at Richmond last year, and were really surprised by what they said back to us.

What we thought they needed, they didn't think they needed. So, I just want to make sure that, you know, we are taking all this time and using all these resources to do this, that this is actually meaningful for them, I am concerned about this.

MS. CAMPBELL-COTLER: I think rightly so. Could you share with us some examples of where the family members' needs were very different from the ones that the staff thought they had, is there an example of that?

DR. BENEDICT: Well, you know, at Richmond it's an acute inpatient rehabilitation core, so we get them,

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our patients and family sometimes two weeks after injury, sometimes two months or three months after injury, and at that point, we were sort of surprised by, you know, it was the physiological stuff, it was the -- you know, the parking here sucks, you know, and we are thinking esoterically, and it is like we need to provide the family support groups, and we weren't ready for this.

There is also the recognition of when people are ready to get this information and how ready they are to hear this information, and I think, you know, our best resource for that are the families, and we can make those guesses and overall got experience in working with families on some level, but I think we missed the boat if we really don't ask them, because it was surprising to us.

You know, we said, well, what about this, and no, no.

MS. CAMPBELL-COTLER: And that's where my concern came in with regard to the target audience and focus groups because the family has to be ready to hear and where should we be targeting, where do we think the families would be able to take in more than understanding

of what it will mean to be a family caregiver and what their roles and responsibilities will be as well as how to getting information about how to manage some of the behaviors and cognition issues that they may be facing.

DR. BENEDICT: I honestly think putting them in a focus group who are going through the process in the present, they don't know, they haven't had time to reflect on it, they can't even listen to what you are saying a lot of times, it just flies right out.

I think one of our best resources is going to be family -- parents or a spouse of a severely injured, severe TBI patient who had been out of the acute phase of the process for a year or so and has had time to sort of think, well, gosh, if this had happened, if that had happened, that would have been more helpful.

I think we can ask them, you know, those folks that are going through this presently, but I don't know how much valuable information we will get, because I am not sure they know.

DR. PRIES: A couple of points. I think one of the things that we had talked about in January was the need to provide clinicians with skills they need to

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assess readiness and to do a really good needs assessment, so that we can determine what families need at the different points in the continuum.

The second thing is to focus our evaluation, not just on the information that we are presenting, but the methodologies that we have chosen to present that information, so that we can assure -- we already determined that we wanted a real multi-modality approach, but based on what we select, is this really the most helpful to caregivers.

MS. CAMPBELL-COTLER: You said something that gave me pause in terms of the clinical skills to do a needs assessment of where the family is.

When I am thinking about the family caregiver curriculum, I am thinking about it as something that the family picks up and turns to with regard to resources for various symptom management or wherever they are, so that they go directly to the point that they are concerned about, that we weren't really including a clinician piece of this, but maybe I misunderstood you.

DR. PRIES: But you have to. I mean I think that you have wonderfully skilled clinicians working with

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caregivers, and they are going to pick up on needs, and they need to be able to assess needs, so that they can refer caregivers to the components of the curriculum that will really help them at that point.

So, I think it is really incumbent upon us to, if possible, share with clinicians some evidence-based needs assessment approaches, so that they can easily integrate into those encounters, that will then help them direct the caregivers to the components of the curriculum that the caregivers need.

MS. COLLINS: Also, I think if you just hand a guide to the family caregivers, it may be interpreted as a brush-off, and you just don't want to do that.

DR. PRIES: And maybe what we need is to, when we package this, to build in a needs assessment to ask caregivers some questions about that once they answer, they will be automatically directed to those components of the curriculum.

DR. CAR-BLANCHARD: Hi. Since meeting with you all last January, my husband was diagnosed with cancer and so I find myself as being the family caregiver, and so it gave me even more insight to the process.

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One thing that I learned is that the needs did not come in a logical order, and so when you are talking about it being all inclusive, I think that is very important, but like you must mentioned, having something on that given day or that given moment, to find this and that, and that and this, because I was thinking when you outline the chapter, and it's not like that. I get too hung up on that.

MS. CAMPBELL-COTLER: Carolyn.

MS. ROCCHIO: Back to your findings about what families need to know, don't we need to know about parking, and all that, but don't dummy it down, because there is so many of us, I wanted to know the day my son was injured, what happened inside of his head.

A friend of mine said when he wakes up, he will tell me what I need to do, but I don't want to know anything before that, so we determine all kinds of different stages and phases, and I think nearly kind of road map to what we are interested in at that particular time. Every brain injury is different, because every brain is different.

DR. BENEDICT: And remember a snapshot of

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families who were on the unit at the time, and in various stages of recovery, and I am not suggesting that we dummy it down, I am suggesting that we pay attention to that teachable moment where they are able and can hear what it is or ask what for what it is that they need, and the other times where they just can't.

I don't think it can be encyclopedic because I think when you put something like that in front of them, they just -- it's too much.

MS. MOESSNER: For years we had a large manual with all the tabs, and it is just too much, and we have really gone down to something very brief, very manageable, but it is always given out direction, you know, this is where you are at, you are in the ICU, now you are probably more concerned about comas and tubes and signs of recovery as opposed to watch community reentry issues.

I assume the staff were handing this or directing family caregivers to this product, because you can't just -- that actually takes some time, you know, to have staff become familiar with what they are handing out and be able to field questions, and so forth.

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DR. FLYNN: I was going to say that I think it will become important no matter what we put into the curriculum to at least have a statement in there that despite all the skills of your health care providers and all, we cannot always anticipate what your needs are, and encourage them to speak up, to ask questions, to define for us what their needs are, so that we can find answers for them, and at least if that's just incorporated into the curriculum, that we encourage you to speak up and educate us, let us know what you need.

We can see if that makes a difference.

DR. PRIES: What I am really trying to do is to develop a partnership, and in a partnership, there has to be lots of give and take, lots of freedom of question and answering and asking, but that is sort of the -- if we can do that I think we will really accomplish something.

MAJ VOGT: Maybe who we should get involved are the case managers, because they are the ones who really have interactions with the families and the patients, as well.

I think it would be great to get the health care providers involved, but if you are looking at

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primary health care, you know, PPM's, who have 15 minutes, they are looking at 30 patients a day, they really are not going to have the time to meet with the family and the patient that they need to, whereas, the case workers, the case managers don't have that time -- probably can hear a lot of frustrations a little better, and hopefully, then, that will help out with the Guard and the Reserve because they will have case managers, as well, whereas, if the Guard and Reserve are having to go, the civilians will go.

I don't know if that is the way to put it, help, get the focus group approach.

MS. CAMPBELL-COTLER: I think that's a wonderful suggestion and what I am hearing about -- we want to do maybe some focus groups with case managers, we want to do some focus groups with caregivers who are about a year out from their caregiving, from the acute phase of the --

MS. ROCCHIO: I would suggest even going further out to pilot it, particularly for those that are several years post, and one good place to do that would be at Haley and -- that there be only PA that have a

support group, and it also include members of the community. So, it would really give you a broad perspective.

MS. CAMPBELL-COTLER: So, if the members of the focus group could be individuals who are caregivers from one year and out, and that gives us a broad range of folks to draw into the group and maybe a mix of time periods would be real helpful.

MS. GOURDIN: I think it is also important to make sure we incorporate a military perspective as well, because there are times when you have veterans that are -- well, if they are transferred to the VA, and they come back to the military, it is good to get the perspective from the clinicians that are caring for these veterans ongoing transfers.

MS. CAMPBELL-COTLER: In a focus group?

MS. GOURDIN: I was just thinking maybe you could incorporate in this focus group, you are saying a year out, maybe a year plus out, four of the individuals that will have a different perspective --

MS. CAMPBELL-COTLER: This has been real helpful, I think, or at least in helping us think about

how we are going to evaluate this curriculum and really get some feedback from people who may have a perspective on what their needs were as they look back on the process that they have been through.

But I also hear that the curriculum needs to address a whole range of things from physiology to behavioral management, to managing the system, to caregiver support.

As I looked at the goals of the curriculum I thought the overarching goal was that we want to reduce the family stress. That's the reason for the curriculum, the families are under stress, and we want to reduce that stress.

Then, I was thinking about it in terms of there is the stress that is intrinsic to the patient that had the traumatic brain injury, their behaviors, their symptoms, their level of cognition, all of those things that the family caregiver sees and has to handle.

We also have the management of behaviors, we also have the management of the system, the things that you have talked about in terms of understanding the military health care system, understanding the VA system,

understanding some of those things.

The more a person knows about that, the less stress he will feel, and then there are the caregiver characteristics, how they manage their own stress, their knowledge of community resources, their capacity to ask for help, those kinds of things.

DR. BENEDICT: I also think self-care and wellness is a really important aspect. It is the one thing that they typically don't want to focus on, they just want to focus on the family member, but, you know, it is so important for them to take care of themselves

MS. CAMPBELL-COTLER: And then the other piece of the curriculum, too, is that we have special populations of caregivers. We have older adults who are caring for their 20-year-old son or daughter who is having traumatic brain injury. We have children who are caregivers.

I think we have kind of generally been speaking of the spouse or partner as caregiver as we have been having our general discussion, but I think we need to special focus on those two populations and their particular needs.

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Does that sound right to everyone?

MS. ROCCHIO: I just have a comment and I am not picking on you, but we need to take care of ourselves. The bottom line is it is very hard to do is suggest how to take care of ourselves, but don't tell us because we get angry.

MS. CAMPBELL-COTLER: Yes.

MS. ROCCHIO: Don't tell us to reduce our stress and live with stress.

DR. BENEDICT: When we have a family education manual where it is in three parts, and the third part is about self-care. It is always a suggestion, and there are suggestions in there about how to manage their anxiety and their frustration and their anger sometimes, and their sadness and all the complex emotions that they have.

You know, we have tips on how do you do this, well, you talk to them, but not telling them you absolutely have to take a day off now and again. But I think we would be remiss to not have something in there, because it is very important. It is important to sort of keep that in the foreground of their minds, too. I mean

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that is part of the whole business of caregiving.

MS. CAMPBELL-COTLER: Yes, I would stand and have brown hair.

[Laughter.]

DR. FLYNN: I was just going to ask a question. As we focus on the target audience that the individual may need different things at different times, and I am thinking in terms of the more moderate to severe, or severe to the subacute basis where things like supportive care and critical care bedside, how to suction a trache, you know, how to change dressings or what have you, and that is something that maybe a family care member who is dealing with a mild traumatic brain injury doesn't have to worry about what the moderate to severe does initially.

So, besides just having a pamphlet with a curriculum in it, will we be able to at least make a recommendation if not establish a mechanism for practical bedside care and instruction for the individuals, and if so, who would be conducting this.

MS. STEPHENS: It seems to me that kind of issue would be dealt with at the facility, discharge

planning and preparing the caregiver. I mean I think it could be referenced, but I guess I kind of am concerned about trying to wrap that up into this module because it is much more skilled and you didn't want anyone to kind of going through that.

DR. FLYNN: We could at least go on record, though, for stating this is a very important part of --

MS. CAMPBELL-COTLER: I assume that many of the facilities have their own clinical standards, they have ways in which they have developed policies and procedure for how trache care should be done, how often range of motion should be done. So, it makes it difficult to do a curriculum that would not get into conflict with some of the policies and procedures at a particular facility.

But I think we do need to be sure that facilities do have handwritten information they can give to the patient, to the caregiver, as well as good instruction, and maybe there are some multimedia approaches.

I mean one of the things that no matter how often you are told something, when you get home with a loved one and you have a procedure to do, it can be

pretty scary, and maybe we have to think about using some technology for walking people through, putting something on the DVD and having directions for how to do a trache or actually demonstration of how it is done.

MS. MOESSNER: I think you can roll some of that, at least in some of my experience, roll some of that into the discussion that you have within your curriculum on transition planning. Okay. You are leaving acute care, you are going to the next phase. You are leaving your rehab unit and heading towards the community.

Here is a checklist of things you need to make sure you know how to do, somebody has spoken with you about it, you know that you are comfortable because that is a time of real crisis and panic for people is during transitions.

And then a second comment, actually the Emory program or the Shepherd's Center, excuse me, in Atlanta, actually has wonderful -- I don't know if anyone has gone to their web site, but they have family information out there, and they actually have videos of trache care, catheter care, wound care, that already exists, and are

free for anyone's use.

So, again, I think there has been a couple comments about existing products' pieces. There is a lot out there already that is, you know, it's on line, web based, free. You can just go right to it, and there is beautiful video, pictures of wounds and prevention and care, and again traches, catheters, tubes, and all of that.

DR. BENEDICT: Liza, who was here last time, I wish she was here, because I do remember her saying bullet the information, give us a link, bullet and link. Don't give me a bunch of stuff, you know, give me the resources to go find the information if that is what I want to go find, instead of putting it all in there.

MS. MOESSNER: With stress, most families that I have worked with forget most of what we discussed anyway, and so again if it's written down and accessible down the road, you are right, sort of a simple format, and if you give something to alarming people, they can barely handle the verbal exchange we have, let alone a large print manual.

MAJ VOGT: This is kind of getting away from

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the focus group, but I got these in the mail. I know DVBIC got one that is already printed out about TBI and stuff, but they actually have a catalog. There is one on questions for severely injured service members, one about the MEV process and stuff. I know a lot of information, what do we do now with TVRL and all that stuff.

It just kind of goes through just short little blurbs, so that might be something we want to use.

MS. CAMPBELL-COTLER: I had a strategic planning meeting with our education coordinators in DVBIC, and I talked with them about the print book, and I was surprised that the font size is so small that people found it useful, but, in fact, because of the tabs, people can turn to the exact information they want, and the font size doesn't seem to be an issue.

They have no feedback from anyone about complaining about how tiny the print is. So, it just reinforces the modular approach, the tabular approach to what we want to accomplish and not reinventing the wheel either.

So, we have agreement on how we are going to focus or approach the evaluation in terms of focus groups

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in target populations. In terms of the curriculum as a whole, we have agreed that we want to do a modular approach, so that a person can turn to the information that they need at the time they need it. Is that correct?

The group has also said that they want to cover the spectrum of traumatic brain injury from mild to severe and penetrating, and the needs of the family caregiver at every stage of that process. Is that right?

So, just kind of holding out the target population here and what we are going to do, the way we are going to address this is in a modular approach, though, rather than in -- now, this is the curriculum for the mild, and this is the curriculum for the moderate, and this is the curriculum for the sphere, but we are going to focus more on issues, behaviors, or functions and the individual can select where they need to go for the information they need. Is that making sense? Okay.

MR. WELSH: Do we want to use this from the last meeting to go by?

MS. CAMPBELL-COTLER: Uh-huh.

MR. WELSH: I think some of the things we

talked about for the last hour are sort of starting around like page 10, it starts capturing some of this information about the modules and what needs to be in the curriculum.

But this might help us refine our focus right now. It sounds like you are trying to stimulate us to lead us through this, and if we use this it might be the catalyst.

Selection of Curriculum Modules

MS. CAMPBELL-COTLER: Yes, because I think we want to go through and develop modules and we need to identify what modules we want to have. So let's move on from there, and move on to a discussion of modules.

MS. MOESSNER: It seems also like in our family, worry about cognition, behaviors, psychosocial reintegration, chemical use, whatever, that those modules would be fairly straightforward to develop, so no matter your level of severity, you can go to a module that applies to where you are right now, but it seems there should be some introductory materials that sort of lays some of this out, mechanism of injury, mild versus severe, making sure they understand initial injury,

severity does not always equate to like residuals.

I think some of that setup is harder to do and explain in a short amount of space and time, as opposed to getting into, okay, cognitive residuals are common after traumatic brain injury da-da, and here is a chart of, you know, memory, confusion, disorganization, how you can manage some of those. I think some of that setup of all of this is tougher.

MS. CAMPBELL-COTLER: Right, and also now, symptoms and an explanation of why someone is having those symptoms.

MS. MOESSNER: Sort of a neuroanatomy and understanding of courses, but trying to do that, that that is more sort of I would direct most families to review that introductory material and set the stage and then pick and choose your modules, you know, kind of set it up in that way.

I mean it seems like there should be some baseline core materials that just sort of set the stage. Instead of somebody going right to high emission or right to behavior, you know, a little bit of why.

MS. ROCCHIO: Anatomy of physiology.

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MR. WELSH: Again, not to reinvent the wheel, but I was just asking Mike I am pretty sure that DVBIC does have a lot of that information already set up, but that basic mechanisms of injury and definition --

MR. DODSON: Dr. Jaffee has been -- there is a quick book we have there that is just absolutely fantastic on TBI, and it answers those questions, and what you are talking about is what happened, and it has to be in English.

MS. CAMPBELL-COTLER: Right.

MR. DODSON: The object entered here and it went through here, and it shattered and then what did they do, well, they put a craniotomy here and they took this out and they put a little --

MS. MOESSNER: Really keeping an eye on.

MR. DODSON: And you have to tell it in English.

MS. CAMPBELL-COTLER: You may have to tell it in Spanish, too.

MR. DODSON: The word craniotomy is probably a little bit too technical, but, you know, they cut the skull.

MS. MOESSNER: And I think just again, one of those complicated issues that is in English so the practical world to describe is just more than the modules and some of those things is the recovery process and high lines of recovery and the inconsistency of recovery and the ups and downs. I mean again that is sort of where I spend more time verbally going over with the others, over and over again versus some of the how-to tips when it gets into certain categories of information.

MAJ VOGT: I think in the interim we need to find some way to sort of emphasize too how much of a factor PTSD is going to take, you know, to become a part of this recovery.

MS. STEPHENS: I wanted to mention that in VA, we have couple of resources that are already developed that may serve as, you know, a stepping stone. We have a veterans health initiative, which is a curriculum on TBI, fairly extensive, it's a four-hour course that you can actually go on -- you can Google it and put in traumatic brain injury veterans health initiative, and there are some practical tips in there.

MS. CAMPBELL-COTLER: To try out for that, is

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that family?

MS. STEPHENS: No, the target is actually clinical providers, but there is really some practical tips for the providers to share with family members in there, as well, so that may be a help, and we also have a manual that Sharon developed for individuals coming to our polytrauma centers, that has a lot of TBI 101, and what to expect. So they may help without having to start from scratch.

MS. MOESSNER: Yes, and in the model systems.

MS. HOLLMAN: I know last time in January meeting, I can't remember who, but somebody had the newest book, it was a red cover, and I purchased that, and that has a great introductory section.

MS. ROCCHIO: I have it with me.

MS. CAMPBELL-COTLER: I also understand, Gretchen, that the entire National Family of Caregivers Association is to develop some modules to help families interact with health care providers. I heard that from Suzanne Mintz, who is head of the organization.

MS. STEPHENS: That may be, but I can't confirm that.

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MS. CAMPBELL-COTLER: Okay. Maybe it is still in preliminary.

MS. STEPHENS: We have a lot of projects associated with NDAA. We are still kind of waiting for some resources to help us implement it.

MS. CAMPBELL-COTLER: I see.

DR. BENEDICT: One of the problems in the curriculum development is that there is so much going on around them, that there are so many resources that handle some of the really core issues that perhaps the panel might want to delegate to the writers and to DVBIC, some of just the meat and potatoes of TPI, and to kind of pull from the existing resources that we know about regarding the anatomy and physiology of what happened in the course of recovery, just some of those things that are, in a sense, boilerplate, and focus more in on the family caregiver component of this, which is really not well described but I saw the medical education curriculum that the VA had developed which had wonderful -- you know, I love the way it talked about the behavior, talked about the reasons why the good behavior, and gave examples of how the family might be able to manage.

I thought that that would be a wonderful thing to include in the curriculum in some form. I like that format very much.

DR. BENEDICT: One other thing that I can give you feedbacks from, there were several people who wanted to know in case someone had a frontal lobe injury, they wanted to know what that means, was there going to be acting -- what sorts of challenges might we face, because when we think PBI, it seems sort of all-encompassing, so if the injury was in the temporal lobe, the injury was in the occipital lobe, and I know a lot of times these injuries are just all over PBI, but the focal point of the injury, and they really wanted to know how that was going to affect their family member's behavior and emotions and what they might see specifically to that injury.

They want to know, I guess the TBI part of it, tell me what happens, because my son had an injury in the occipital lobe, what does that mean.

MS. CAMPBELL-COTLER: You had to operationalize it, and there may be some broad concepts that the clinician can provide, that the family caregiver is going

to have to look at and really see how it is operationalized, so it reinforces that partnership.

MS. ROCCHIO: And I think a really good way to present that -- and I have, gosh, it must be 20 years old now -- it is just a picture of the brain with the breakdown of here is the frontal lobe, this is what is controlled with the frontal lobe. I think the families understand that better and then when you get to limbic system, spell it out, emotion, et cetera, the temporal lobe and music, and I think they understand that better in diagram form, and you don't need a lot of broad explanations of that, so they know there is going to be problems in executive function.

DR. BENEDICT: Or with balance.

MS. ROCCHIO: Right.

COL JAFFEE: You just raised the point I was going to make, which was this information can be debated in any number of different ways, it depends on the medium in which you are doing it, be it quick book, or what types of illustrations that you have, and there is a lot of things out there, and just kind of setting the stage for our presentation that we are going to have a little

bit later from the Center of Excellence for Medical Multimedia.

They recently took a book out there and synthesized it to develop a script the type of script you would apply to a multimedia production with images and films, and so forth, may be able to kind of share some of that more with you when they do that presentation.

But as far as collating what is out there, you have to also kind of plan for what is the medium and what type of product was the output, because the way it's synthesized may look at little bit differently depending on the medium.

MS. CAMPBELL-COTLER: And we have to do these modules in a variety of media, print, interactive.

DR. BENEDICT: So, is there some consensus that we can look at what is boilerplate or core in terms of information that all families should have regarding some of these topics, and that we will delegate that back to the DVBIC headquarters to pull together the best information and bullet it and work with our health education writers to do that, and focus our attention more on the caregiver, caregiver needs.

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Let's focus on caregiver, the modules related to caregivers. I'm thinking of two things at the same time, sorry for stuttering. The caregiver needs with regard to -- when I think about mild TBI, I think about the caregiver needs when it hasn't been identified, the concern, the sense that maybe their loved one hasn't recovered from their military experience the way they had hoped, and they are seeing some behaviors that might be indicative of something having happened in the military setting and the person is not functioning well in their live, you know, six months to a year after his stroke, but that would be around the mild.

I think maybe one of the most critical things that family caregivers need to know, what to do if they see certain behaviors and where to go and the level of information that they might want to collect as they go forward within the system to be able to describe specifically what their loved one is able to do or not able to do.

MS. COLLINS: Kind of a recognition of some possible symptoms that they are seeing.

MAJ VOGT: That might be hard to get out

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because that seems like something that has to come more -- this, unless I am understanding wrong, those products I thought were geared more towards those diagnosed with TBI, and we are not going to be getting it out to every single family or every single attorney.

I know that the Army has pushed out every service member, you know, learning about TBI. I think that is where more the focus has to come from as opposed to us trying to deliver that information.

COL JAFFEE: Just to clarify the program, they have a teaching program, so it is a very brief briefing, everyone who wears the Army uniform had to complete on line just basically it is a very brief education, TBI and concussion, what are some of the symptoms, if you were involved in an event where this happened and you are having some of these symptoms, get checked out, that sort of thing. That is basically the extent.

MS. CAMPBELL-COTLER: And that can really just go into the approach of looking at symptoms, you know, a module on fatigue, a module on passivity, a module on irritability, and perhaps depending upon the part of the brain that was affected or whatever, does it matter if

it's mild, moderate, or severe if you are talking about fatigue or about some of these underlying symptoms.

We are going more towards a functional or system based module once again.

So, let's just talk about identifying some of those very modules that we think we want to have in the curriculum on symptomatology.

DR. PRIES: Sometimes it is easier to do these at the beginning than to try to do it later, but as for identifying modules, to identify both information and competencies and skills at the same time, it makes for a lot easier evaluation process as we were sort of tasked to do competencies, which is really important, not just so people know, but what can they do and how well are they coping.

CAPT HEPPEL: We were just thinking that rather than having a module on each and every one, that would get pretty complex on irritability, on and on, but we could have a module on behavior, and then underneath that have some of the ones we see.

MS. MOESSNER: Do you want communication separate from behavior? We usually separate it out

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communication change with difficulties, cognition.

DR. CAR-BLANCHARD: Specific caregiver issues.

MS. MOESSNER: Managing behaviors,
communication.

DR. CAR-BLANCHARD: Are you talking about how
to communicate with the person?

MS. MOESSNER: Yeah, I think the person has
communication residuals, which is fairly common, as a
caregiver, how I deal with that with somebody who doesn't
normally communicate as effectively anymore, what are
those practical things that helped me, say what the
unmanaged behavior, cognitive changes.

Three is just another one of those categories
where people sometimes have residuals and family members
get frustrated when someone can't communicate in the same
way they used to.

DR. BENEDICT: Then, I think we need to give
them tools on how to address this problem, how to manage
the problem.

They have got what they want to be looking for.
They have got the information to get on the net and get
all of this information that they are looking for. Help

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me with it.

MS. MOESSNER: The practical strategy is over and over when I get home, and what am I going to do here, you know, one of the most practical strategies in terms of communication, behavior, thinking, safety is huge, relationships.

DR. PRIES: And another thing we identified was that the system management function that caregivers face, do we also need to build in there in terms of either communication or system management, how you can better get your needs, express your needs and get them in a way that isn't going to anger. Well, I use that word with reluctance, but annoy.

MS. CAMPBELL-COTLER: So, we have got behavior management and we have got systems management, that the caregiver needs to be able to develop over the course of time. Advocacy is another topic we need to address.

DR. BENEDICT: Early on, you absolutely can't do that, but later on, after they are into it two or three years, they start to realize that sometimes they need to go out there and actually start beating the bushes and get more active.

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MS. CAMPBELL-COTLER: Advocate on behalf of your loved one.

DR. BENEDICT: Particularly when we are talking about these very young spouses who are 18 or 19 or 20 years old, they don't know how to do that.

CAPT HEPPEL: I think I have mentioned this before this group, but the Federal Government provides funds to every State and Territory for protection and advocacy for survivors of traumatic brain injury and the families and part of what they do is training in self-advocacy, as well as providing advocacy as far as going through the legal system if that is necessary.

So, that it out there and if we can somehow get people to link up with them --

MS. CAMPBELL-COTLER: Now, is that system different from the protection advocacy system for disabled populations for seriously mentally ill and other groups, or is it the same?

CAPT HEPPEL: It's the same. Every state has a court-appointed. They get many funding streams, and so they will get some in terms of substance abuse and mental health for certain populations.

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MS. CAMPBELL-COTLER: Thank you.

Please refer to the notes of a meeting to jog your memory about the modules that we discussed, but I don't want to limit us to those either.

MAJ VOGT: So, is the module going to be like it will describe the symptom and then give a practical strategy?

MS. CAMPBELL-COTLER: Yes. It might explain one symptom is deferring.

MAJ VOGT: Bullets, this is what the symptom is, and this is why, and these are tips on how you can do it, and maybe just do one or two liners for each.

MS. CAMPBELL-COTLER: Also, let's move on from the behavior module to systems management and the kinds of things we want to include in that. A lot of it already exists, maybe the quick book may be all we need, but that needs to be looked at by someone on the panel to tell us if the quick book is positioned on there. I am thinking of one on benefits and services.

Is that sufficient or if we need to expand on that within the curriculum?

MS. CHIASSON: This is all behavior,

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communication.

MAJ VOGT: I think they are different.

MS. CAMPBELL-COTLER: They are different, but we are going to call it the behavior management component, so there will be some modules underneath that, some specific modules, helping the caregiver with behavioral management, and then we are helping the caregiver with systems management now, and just some of the ideas that we might want to consider in modules.

First of all, to evaluate what currently exists to help families do systems management as the first place to start, and then from your experiences, what do you see as things that we should really address?

DR. FLYNN: Meg, is there anything in the systems management literature or module with respect to unique military situation in terms of family caregivers, who themselves are not beneficiaries or entitled to or special exceptions made or whatever?

I refer again back to the January meeting and I think it was Liza who said that while she was caring for her brother who was severely injured, she couldn't even get in to the PX to buy something because she wasn't a

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beneficiary.

We talked about trying to have the influence of this committee or this panel on changing things like that, but again I am not even sure myself if somebody were to say to me what does the government provide for families to travel long distances, once they are here, to take care of their loved one, you know, do they all get put up in the Fisher House, or do they have to pay out of their own pocket, how much do they have to pay, and what is the difference between a non-beneficiary caregiver in this situation like a brother or sister versus a spouse, who is a beneficiary,

MS. CAMPBELL-COTLER: Those are very good points.

DR. FLYNN: Obviously, if there is a financial hardship that goes with this, the stress on the caregiver is going to be significant and greater.

MS. ROCCHIO: This is the missing piece under so much literature out there on taking care of people with brain injuries, but when you come to the military, there is nothing that is captured in one place that a military family can access, and I think Liza made that

very clear the last time. That is the only single link here.

DR. BENEDICT: And that was substantiated when they talked about what was stressful for them and we talked about their time with the military treatment facility and then their time at the PRC.

Almost every one of them mentioned the paperwork, the paperwork, the paperwork, don't understand why I can't apply for this, if I can apply for this, what am I eligible for, do I get per diem and am I on non or whatever it is NMA, non-medical attending orders, yes.

You know, just don't, sort of practical questions that to them were very important, very distressing because they couldn't get the answers, or they got different answers from people, or they mover from MTF to VA and got different answers, so that part was really stressful for them.

So, you are right, that is a piece that those are the questions that come up all the time, sort of logistical questions.

COL GIBSON: Let me add to this. I think you all need to take a briefing from the Board of Transition

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folks, because they are going to answer some of these questions that you have.

What you are talking about is pre-February 2007. In particular, the Army and the Marine Corps have went a long, long ways over ensuring that that caregiver, beneficiary, family member, et cetera, of our wounded folks are, in fact, given that information, advocates assigned to them, helping them through the system, helping them through the paperwork.

So, you guys need to take that -- I will try to help you get that set up.

MR. DODSON: Just a comment to follow on, the warrior transition brigade at Walter Reed and other locations, different times, I think Ramsey has a brigade, the Marine Corps Warrior Transition Regiment.

Those are very good. Each patient has a Staff Sergeant, Sergeant First Class, a Captain, and their case manager working with them. The problem is that the caregiver doesn't know enough about the military to know what question to ask.

COL GIBSON: That is a matter of time and experience for the team to know what questions should be

asked. Bragg has one, Vermooz [ph] has one.

CAPT HEPPEL: I have a question about that. Both services, do they also help the caregiver understand about the disability rating system in the veteran versus the DoD, so that it is really important to know what questions to ask.

COL GIBSON: That's the PEBLO, and it is part of that product. There is gaps. Don't underestimate the fact that there are gaps in the system, and I am not sure that the Air Force has anything comparable because we simply are not seeing those types of wounds in our Air Force people at nearly the rate that the Marine Corps and the Army are.

But you all need to take it because you can make the comments to fill the gaps, because it's not seamless, I doubt if it's ever going to be seamless, but we can get back and folks like you can help us.

MR. DODSON: Once again, and you can tell Ellen that I am not criticizing her, I have found in working, and I think I have worked with about 18 Wounded Warriors since I started this, the PEB liaison officers, he said the PEBLOs, are not that knowledgeable. That is not a

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criticism of the individuals, it is just that the system is very overloaded and over 700 patients at Walter Reed alone.

So, you are talking about a lot of stuff. Then, you get out into the CBHCOs for Reserve and National Guard personnel and you get even a lower level of awareness and knowledge. Some of the associations like the DAV and VFW and the American Legion, Purple Heart Society are working to help the Wounded Warriors in their MEB\PEB process and then also in their VA disability applications.

In Walter Reed, the best one is DAV, in other locations it's VFW. There are assets available and I don't mean to criticize PEBLOs, but I ran the one that was probably about as knowledgeable as a wok. I knew more about the PEB and MEB process after having gone through it than they did.

COL GIBSON: The other thing that is happening that you should be aware of is that whole disability evaluation system is B, is under review being reengineered, a lot of stuff going on between DoD and VA and the health care process. There is a pilot program

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here in town. We could probably get set up a brief for you all.

MR. DODSON: That would be good.

COL GIBSON: Because this is a moving target.

MR. DODSON: That pilot program is working very well by the way. I have already had some of our patients go through it.

COL GIBSON: It is hard for these PEBLOs, it is hard for them to keep up because the process is changing as we are going along. The other thing -- and this is one of the things the Dole Commission pointed out, it is something that the Independent Review Group pointed out, the IRG, the PEBLO is set in a position where he is supposed to be your liaison, but, in fact, the second you go into the disability section within DoD, it sudden becomes adversarial by definition.

MR. DODSON: Yes.

COL GIBSON: So, there is all kinds of issues at hand here, and Yes?

CDR MILLER: Yes, sir, and I do concur, and I think that the PEBLOs are personality driven as well, and you could get an absolutely exceptional PEBLO that has

been round for a very long time and knows a lot of things, and then you can get the ones that are absolutely horrible and I know the Marines that we have go through the system, have had both sides of the spectrum.

I think that where you are going with this, which I am sitting here kind of thinking, is that you really would like the Federal Government to put a one-stop shop benefits counseling office into play where, you know, they are going to include all the VISNs and the -- it's a one-stop area where somebody could actually get the real skinny on benefits because right now there really is not a one-stop shop place to get the skinny and to get the resource manuals and to have a veterans resource center where you can go and ask the specific questions and do that, and maybe that is something that comes as a recommendation out of something like this.

COL GIBSON: It would veer in the recommendations of the other groups. What we are really talking about is the one-stop shop plus an ombudsman. You go into the system, you have got this person who is a knowledgeable advocate to walk you through. The issue is here we are talking about the folks, what we are doing

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apparently a decent job with, I would say fair, is the severely injured that end up in a facility as an inpatient.

What about mild TBI that having some residual problems in an outpatient facility at Fort Riley, where is that group? Now, Fort Riley has a Warrior Transition Brigade, and they are helping with it, but that idea of a one-stop shop and having somebody as your advocate as you go through this billing system needs to grow.

MS. CAMPBELL-COTLER: Colonel Gibson, you mentioned the possibility of two briefings. How can we go about getting those?

COL GIBSON: I can help you.

MS. CAMPBELL-COTLER: They are available on line?

COL GIBSON: No, we will bring people to the next meeting. We will bring folks to you.

MS. CAMPBELL-COTLER: The next meeting we will have the curriculum finished.

So, we need to think about either having an interim meeting or an on-line way of doing that.

MS. CAMPBELL-COTLER: It's really hard to know

what we need to include in the system without retaining what currently exists, so we are going to have to learn more about that and be sure that we cover the gaps, and I am glad you identified that there really are gaps.

COL GIBSON: It is more for background information for you all, and I can see you progressing with a curricula here, folks and TBI folks that span the scope of TBI. You have a report that comes up at the end of this whole process. Therein is where you are going to recognize gaps that even your curricula are not going -- you know, it's inherent government activities versus a curricula.

MR. DODSON: Every other Monday, at Walter Reed, there is about a two-hour briefing on the benefits MEB/PEB process that is given to the families and/or any of the Wounded Warriors who are outpatient and ambulatory even in wheelchairs. Walter Reed is doing a pretty good job of that.

The DAV at Walter Reed has recognized the adversarial relationship of the PEBs and they have got several hundred attorneys in the D.C.-Maryland and Virginia area who have volunteered to represent the

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soldier, sailor, airman, marine corpsman at the PEB free.

So, we are signing up all our guys for a free attorney because that kind of puts people, you know, before you make a decision on sick disability, you have got an attorney standing there, it makes you a little bit more careful.

COL GIBSON: Part of this disability reengineering issue is that the VA folks will be setting the ratings and the Department will accept them, period. That takes --

MR. DODSON: One rate, there is only one rate.

COL GIBSON: One time, done. Accepted That takes some of the adversarialness out of the situation, but by definition, it is you as a service member against the government, and it is always going to be to some degree a bit of a problem.

CDR MILLER: Colonel, we don't have anybody that has actually gone through the entire system -- oh, I think one person, that was 100 percent rated. Now, I think in the next 30 days or so, we are going to have some people that are going to hit that mark, and I think there is going to be some interesting findings that are

going to come out of that.

I know that there is expandability into the program, and they have already looked at expanding this pilot program to other areas in the country, so what you are saying is actually very true and it is going to not only affect the people that are local here, they are already targeting San Diego and some other areas that they are going to expand this project to.

What happens out of that is going to be very interesting.

COL GIBSON: The unfortunate thing is that folks at the OSD level are incredibly interested in making this work well and having it to be a success, and as they identify the screw-ups, the things that people who have gone through the gaps, the problems, their goal is to fix it. Golly, wouldn't it be great if two years, three years, we actually have a system that favors the service member like Congress does.

MR. DODSON: Just a comment. That pilot study that is working here in Walter Reed and the VA, there is only one disability rating program that we use in the VA's criteria for the percent disability is working very

well. Now that the patient does not have to go through two different sets of disability ratings, however, there is no VA disability category called traumatic brain injury.

You have to go in and pick up over the some 30 years some 10 symptoms, effects, et cetera, a TBI and apply for each one of those. I have done it and the VA is, without being too harsh, ignorant about PBIs. Now, they do have a great category for CTSB.

COL JAFFEE: I can say that that is actually under revision.

MR. DODSON: I sure hope so.

MS. CAMPBELL-COTLER: In the next few minutes, let's just go through a little bit on the caregiver needs. We talked about the direct needs of the caregiver, some of which has to do with being progressive, for example, how that might be obtained, how you ask for help.

DR. CHURCH: How about counseling?

MS. CAMPBELL-COTLER: Counseling.

DR. CHURCH: Family counseling.

DR. FLYNN: Financial assistance.

MS. CAMPBELL-COTLER: Financial assistance.

Do you think anything on home modifications?

DR. CHURCH: Yes.

MS. CAMPBELL-COTLER: Sometimes.

Assistive Devices?

CAPT HEPPEL: Transportation.

MS. CAMPBELL-COTLER: Legalities.

DR. CHURCH: How to be an advocate.

MS. CAMPBELL-COTLER: How to be an advocate.

Benefits that include being able to go back for training.

MR. DODSON: She's from the VA, but I am working with kids, we are actually training spouses using the VA money, education, proved job opportunities, et cetera. The VA is very good about that.

MS. CAMPBELL-COTLER: Good. People need to know that that is available to them. Developmental needs of an 18- to 22-year-old who might be the spouse of someone who was hurt in the war. That person is still in late adolescence in many ways, you know. They have a lot of growing to do .

Something about caregivers' ability to accept

where they are, their own level of capacity to cope with this, their maturity level. That certainly plays into how they get their needs met and also the level of needs that they have.

Under special populations we have older adults of caregivers, people who are perhaps as old as 65 or 70, who now find themselves with an adult child at home, who may be anywhere on the spectrum, and what resources, what education does that have for them in terms of what they thought they were facing in their retirement years, and not really providing, continuing their parenting role at a time when their emotional and perhaps financial resources are not what they were when they were younger.

MS. ROCCHIO: The primary issue there is who is going to take care of --

MS. CAMPBELL-COTLER: For the older adult caregiver, it is really planning for the future, estate planning, and caregiving plan, who will take on that role.

DR. CAR-BLANCHARD: It is overall financial planning. They might find themselves in control of the books where their spouse might have been in just general

financial planning, and another point I want to make is either this part or someplace else, kind of a -- I don't know what you would call it -- but an opt-out plan if the person realizes I can't do this.

MS. ROCCHIO: That happens frequently.

DR. CAR-BLANCHARD: Well, I had patients dumped at the ER over the weekend type of thing, just to ensure that the person who had great injury is not abused, molested, or dumped off somewhere, just an opt-out.

MS. CAMPBELL-COTLER: Uh-huh. Helping the caregiver to recognize their limitations, what they can do.

DR. CAR-BLANCHARD: And then what do you do?

MS. CAMPBELL-COTLER: And the resources, then, the next steps, if you recognize that, you just can't fulfill this role, then, how do you transition it responsibly?

DR. CAR-BLANCHARD: Yes.

DR. BENEDICT: And then one other thing we left out, the issue of vocational rehabilitation for the patient, which I think with mild TBI is a really big factor, getting them back into the community, the

community re-integration, back to work, not adopting a sick role. It may be a link to where if you have got a link to where you can go to get information.

MAJ VOGT: Can I make a suggestion? I feel like we have said a lot of things over and over again, and I was wondering if there is a way to say, okay, these are the modules we want, we want on system, we want on business, and then maybe break out into groups, something where we can actually list as opposed to I feel like we are saying making the same list over and over.

MS. CAMPBELL-COTLER: You are right, we are, and the plan was that very thing, to identify the modules and let's have people work in small groups to really flush them out to determine the contents of the modules.

I think what happened was that they got a little turned upside down and so the careful way I had planned that didn't work out.

DR. BENEDICT: But I heard three modules so far. I heard the information the TBI 101 --

MS. CAMPBELL-COTLER: Yes, the behavioral management piece, the systems management piece.

MS. MOESSNER: For me, even under behavior like

to me cognition is different than behavior, that is different than communication, so I think even those can be separated out.

MS. CAMPBELL-COTLER: So a module on cognition, a module on behavioral management. We have that one.

DR. CHURCH: And communications.

MS. CAMPBELL-COTLER: Communications. And then maybe one on resources.

MS. MOESSNER: I don't know how you lump things like driving, returning to work, you know, but there is all that community re-entry, longer term information that tends to get batched together somehow.

MS. COLLINS: I think community re-entry is good.

MS. MOESSNER: Yes, these are sort of later things, so if this isn't important to me now, but it will become important, again, you know, relationship building.

MS. CAMPBELL-COTLER: We are ready for lunch. Just going back to the specialized populations, so I don't want to ignore children and the role that they are apt to play in terms of providing maybe emotional support to the caregiver, as well as typical and emotional

support for the individuals who have had CPI and the toll that that can take on the growth and development of a child, and how to mitigate that, because in some situations the child does have to play an adult role,

MS. MOESSNER: Yes, how do you enable the child, the adolescent to be who they are in development.

DR. BENEDICT: One other thing. I think it would be a good idea if the group agreed, it might be a little redundant, but because there are some things that actually go under each category, that it would be good to mention them more than once, not to say in one section if you want to go into vocational rehabilitation, and also if you want to do this, because the person might see the first part and not remember maybe four other things, so it wouldn't hurt to repeat it.

One other thing. I think redefinition of who is in the family, who died in the family, I mean we talked about that, trying to determine who is in and who is out.

MS. MOESSNER: I think another broad category can be emotional changes, because, you know, depression and those sorts of situations are very, very common.

MS. CAMPBELL-COTLER: Any last words before we break for lunch?

DR. FLYNN: I just had a suggestion. As far as the needs assessment, it is interesting to find out which target behaviors, you know, give them the most stress and the most problems. You have somebody who is very apathetic and because of that apathy they may be a little bit easier to take care of at home physically, but somebody else just totally disinhibited or irritable and aggressive, what have you. The target behaviors of the individual patient can make a big difference in terms of how that character reacts to that.

MS. ROCCHIO: And that changes every time.

MS. CAMPBELL-COTLER: Why don't we break for lunch. and resume at 1 o'clock.

[Luncheon break.]

MS. MOESSNER: I think we will go ahead and get started, if everybody will take their seats again.

COL JAFFEE: That was an interesting morning, which I think set the stage, and I think we are setting a foundation to really start organizing, even the modules. So I am very pleased that we have joining with us this

afternoon, our guest from the Center of Excellence for Medical Multimedia.

So I want to officially welcome Colonel Mauffray who by training is an ophthalmologist, but because of his additional expertise in multimedia, production, and computer issues, he was actually hand-selected by our Surgeon General to take the reigns of the Center of Excellence for Medical Multimedia and has been doing a great job of that for the past couple of years.

With him is Captain Migliore who comes to the center with a background from community and public health nursing.

So they provide a broad perspective. They are going to tell you about their center which now is the only DoD center totally dedicated to medical education along this line.

Some of you got something that looks like this. This is an excerpt of one of the scripts that they are developing for a product, as we talked about before, that gear towards patients and family caregivers with the educational aspects that we talked about this morning,

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kind of the locations in the brain, this and that.

That script actually covers all the modules. It is close to a hundred pages long, and we will make that available to you. It will be provided for you as just a sample of what they have with the outline and how they have organized that information, as well as some of the specific sections dealing with the family caregiver.

Like I said, what we hope to learn is give everybody a feel for the potential that exists with the multimedia format medium and to kind of hear more about the other TPI project that they are working on and sort of put our heads together to talk about possibilities for moving forward.

So, with that, I will turn it over to our guests.

**Presentation from Center of Excellence
for Medical Multimedia**

COL MAUFFRAY: Thank you, Colonel Jaffee. I appreciate the opportunity.

I apologize for interrupting or disturbing your agenda for the day. We had a lot of fun getting here. The day started at 6 o'clock yesterday in Colorado

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Springs and ended about 1 o'clock this morning, without bags and everything else. So it has been fun. We have been driving all over D.C. today. So it has been a lot of fun.

[Laughter.]

COL MAUFFRAY: What I would like to do first is just tell you a little bit about the Center of Excellence for Medical Multimedia and then show you a little bit about some of the projects that we have worked on in the past that are fully developed and in use, and then talk to you some about what the Traumatic Brain Injury project that we have been working on entails and how that may interface in what you guys are doing here, provide a stepping stone for your mandate.

The Center of Excellence for Medical Multimedia is an organization that was established in 1996 by the then-Surgeon General, and his idea at the time was to harness technology as a way of advancing the educational opportunities that we are providing for our patients.

As we were listening earlier, there were a number of buzz words and key phrases that I heard you guys throwing about that were critical. One is the

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partnership that we have with our patients.

As the medicine has evolved over the years, what we have seen is that we have gone from much less of a paternalistic approach to medicine where the doctor says the patient does to a very cooperative-type arrangement, where we expect our patients to be partners in their health care and understand the disease processes that they are dealing with. That participation is very important.

One of the key things, though, that is missing in the partnership quite often is one of the things that we find very necessary for our providers, our nurses, our technicians, our doctors, is knowledge and education. If we expect our patients to be equal partners in health care and sometimes even a bigger than 50 percent partnership, then they need knowledge and education as well as to how to be those partners. So that is the goal of the center to be able to advance those partnerships and make sure the patients have the tools that they need to understand the disease processes that are going on.

One of the things that we are often told, as we have gone around to visit over 35 of the 75 medical

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centers that the Air Force has, and invariably when you ask the question who provides the patient education, who tells the patient about the disease process, the answer is, oh, the doctor in the clinic.

As one of the doctors in the clinic, I can tell you that the time is just not there to do it in the way that you need to do it.

If you have a 35-year-old captain or staff sergeant that comes into your clinic and you are going to make a diagnosis of high blood pressure, you don't have the time to sit there and actually go over the basic anatomy and physiology of what it means to have high blood pressure, with the long-term consequences, and why it is that you are going to have them take a medication that may cause exercise intolerance, chronic cough, or impotence or something like that, when they feel perfectly fine.

They have no symptoms or anything, and you need them to understand that at that moment that you need them to be a partner in their health care to understand the disease process and why it is so important for them to take these medications that may not otherwise want to do.

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So that is one of the things that it is really hard to do in the clinic when what you are doing is you have a 15-minute slot of time, and during that time, you are going to have to diagnose, evaluate, document, fill out the prescription forms, deal with the great military life, and schedule follow-ups. All those things are being tracked.

One of the things that is not being tracked is did you actually educate your patient in the disease process. If I don't code something, they will come hunt me down. I can assure you of that. If I don't provide an adequate piece of education, it is not really something anybody is looking at.

So, giving people the tools to make that easier, to give them that provider-level knowledge at no cost to provider is what is important to us. So that was the goal of the center, and that is what we have been doing the last number of years.

We currently have about 74 products that we have on our website that we provide to the Air Force. We provide them free of charge. There is no shipping charge. They come to our website. They place an order.

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They are shipped around the world and given out free of charge.

We currently send out about 100,000 products a year around the world out of our little office. You are looking at two-thirds of the staff being here right now, and so it is quite an undertaking to make that happen, but it is an important thing to do.

So those projects range anywhere from cardiac disease all the way through to asthma, refractive surgery, pregnancy, and so they cover a wide variety of topics, as well as diabetes, and currently, we are working on two projects that are interrelated. One is traumatic brain injury, and the other is post traumatic stress disorder.

These actually began about a year, year and a half ago, with some initial discussions and have advanced to the point that now we have on contract a development piece and then the script which, as Dr. Jaffee had said, is about 100 pages long. So you have a very small sample of what is there.

It goes over a lot of what you guys have been talking about, some of the words, as you guys have sort

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of been hashing it out. We remembered discussions taking place on our side as well.

In fact, Dr. Jaffee was just out with us in Colorado Springs, as we had one of our development conferences, kind of trying to streamline this, and one of the really difficult tasks -- and you guys will confront this as well -- the amount of information that can be had is vast. So you have to focus on what it is that you really need to convey to the patients and how you are going to convey it, and that how you are going to convey it is one of the things I would like to sort of show you here.

The methods are as vast as the imagination as to how you can try to get information to a patient, whether it is one-on-one patient consultation, which would be fantastic if we had the resources to do that for every single patient. You can have a printed document, whether it is a pamphlet, a stack of papers, something that you xeroxed, or you can kind of go to a next step and look at how can you take technology, harness technology to provide that information in an engaging way.

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One of the things that is really difficult, especially with today's very technology savvy young patients as they come forward -- and a lot of these folks that we are dealing with, we just heard earlier about the 16-, 17-year-old life of one of our service members. So these people are exposed a lot to the kind of technologies we are talking about and engaged by and less so by printed media. So that is one area where this kind of thing can take place.

Our programs are primarily focused or primarily developed in a computer-based format. So, either it is a fixed media, a CD-ROM that you put in your computer and it executes and runs off that computer, web-based, or DVD video where you actually put it into a DVD player and it plays that way, but they also include within those programs all of the medias that we have just described. So there is video. There is animation. There is graphics. There's text. So it is a wide variety. It is all pulled together into a single modality.

One of the nice things about that kind of presentation, though, it goes back to the description of the amount of data that you give somebody. Are you going

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to give somebody an encyclopedic amount of data? You can't do that if indeed what you are going to do is take the Encyclopedia Britannica and set it on somebody's desk. They are immediately going to be turned off.

But when you approach it from a technology standpoint, you can package that information to where you are handing them a CD-ROM that has a few bites of data on it or is completely loaded. To them, it is not really visible, so long as it is laid out and programmed in such a way because it is easy for them to navigate. They can get to the information that they want easily. Then they have that encyclopedia, but they only have to touch those little pieces of it that they want.

So let me just read you really quick a couple of the programs that we have recently developed or that we have developed over the past that let you see some of what we are talking about.

This first one I was going to bring up is a program -- and we just had lunch. I am an ophthalmologist by trade. So, if eyeballs bother you, we are about to see a little bit of an eyeball. So I warn you in advance.

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[Laughter.]

[Video presentation.]

COL MAUFFRAY: So here we have just a simple laid-out menu where you can go in and directly access whatever bit of information that you want.

So we will just look at the human eye, and this just talks a little bit about what the cornea is.

[Video presentation.]

COL MAUFFRAY: What I am going to show you here real quick is one of the things we have been wrestling with this particular project is how do you take what is -- when you actually sit down, do you want to read about or learn about the anatomy of the brain, the anatomy and function of the brain. It is a very, very difficult topic, and we have struggled with this one now for the last couple of months on how do we take that and simplify it, but still have it be meaningful because a lot of what the patients and their family members will be exposed to are medical terms. They will talk about the occipital load and things like that. So they need to know it, but how can you present it in such a way that they understand it.

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So one of the concepts that we have been working with is developing what we call an interactive brain model. What we will have is a 3D model of the brain, and as you go through the brain, it will be able to identify those particular areas of the brain that you are on, and it goes back to this discussion earlier about the fact that somebody was shot in the frontal lobe and they have frontal lobe damage, how does that affect their behavior.

So, as you go over this brain, you would actually be able to roll your mouse over that particular area. You click on it. It tells you that that is the frontal lobe of the brain, here is what it does, here is what kind of behavioral abnormalities you might expect or behavioral differences when somebody has an injury or the occipital lobe that affects vision or the temporal lobe with memory, so doing it in an interactive way without just flooding somebody with the medical terminology that really is inherent to the anatomy and physiology of the brain. So that is the concept there.

The problem with that, though, is that is great for the computer-based version of the project, but if you

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take it to the lowest common denominator format, which for us tends to be DVD video-based, hence, the penetration of DVD video into the home is over 94 percent, so most people have access to one of those, but if you do that, you lose that interactivity, so how do you take that and again convey that anatomy and physiology to them.

So we will have sort of a dual version with the video components to it, but trying to use simplified terminology, so that we have something that can go into the DVD video. It is one of the challenges that we have.

As you try to take something, you have a derivative product, you have a website or you have a CD-ROM, how do you get a derivative video out of it when there is so much content that ends up being lost, and that is one of the things that we often try to make sure people understand is that the most rich version, the most interactive version, the most engaging version is going to be that computer-based version. You just can't duplicate that on DVD video.

As we see some newer technologies coming out with now Blu-ray, it is actually a computer-based java

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language, and so you can actually program that. The problem is the penetration of Blu-ray into the household is measured in the thousands, not in percentages. It is just too small a percentage.

But what you see here is a little interactive eye. This is kind of a simplified version of what I was talking about. You can see as you mouse over this area, it gives a little animation of how the retina works. You see the light entering and then how the light is actually transported out and then back down through, the signal back down through the optic nerve.

One of the things that people don't actually realize is that as light enters, it is actually picked up as signal. It passes all the way through the retina, and then the signal comes back out in the front of the retina and then back out to the optic nerve. So, when they originally programmed this, they even had that backwards.

It was going the wrong way for us.

So that just gives you a little piece there. Here it talks about what does it mean to be a hyperope and a presbyope. So, with a hyperope, meaning that the images come in, that is what people normally think of as

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farsighted.

That is kind of a misnomer. If you are farsighted, it means you don't see well at near or distance. You just see better at a distance, but you can see the image is focused out here in space.

Whereas, if you are nearsighted or myopic, you can click here, and you can actually see that the image is focused in front of the retina. You can now visualize the fact if you push that image closer to the eye, you would force that focal point back onto the retina and actually see. You can actually see something clearly near, and then presbyopia there.

So this is just sort of a real simplified version of what we are kind of envisioning for the interactive brain, and again, here you can look at the lens of the eye. It tells you what it is, the iris, where the fluid inside the eye is made.

So this is the refractive version of it. So it wouldn't be complete if I didn't show you a little bit of refractive surgery. This is what I was asking you about earlier, if anyone was bothered by the eye.

LASIK. Does anybody have a preference?

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Everybody is getting LASIK now.

[Video presentation.]

COL MAUFFRAY: The other thing we do is we also provide those same -- if you went right back to that, you can see if you click here, you get the same content as a text-based document. So, if somebody doesn't watch the video, they can just read through it and get the same information.

What I would like to do now is click over to a different program. One of the key aspects to the programs and the patients is that all of our programs is coming through with real patients. So these are people with whatever it is that we are talking about, who really had it, who are really dealing with it.

So the one I would like to show you real quick is our program on breast cancer. The reason I say Frank played an important role in that, when we were filming the piece for refractive surgery, he mentioned that his 35-year-old wife had just undergone mastectomy and was just completing her six weeks of treatment for breast cancer, and that she really wanted to be in our program.

So I am going to skip through and just come up

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here to a resource section. It allows me to get direct access to some stuff. They are embedded throughout the program. That is just kind of a quick way to get there.

That is Frank's wife.

[Video presentation.]

COL MAUFFRAY: So you can see how that gives you a personal connection to those people in the program.

Let me just let you take a look, because that one can be sort of a downer. As you listen to it, some of them talk about the sisterhood of cancer survivors. Listen to the music. It picks up a little bit.

[Video presentation.]

COL MAUFFRAY: So there was some good in it.

The other thing that we are able to build in there, what you saw were grouped together. So they were all just put together, but each one of those segments that you saw was actually grouped to where it was appropriate in the program. So, as we talked about diagnosis, you would see the real patients talking about their own diagnosis, talking about the treatment that was embedded within the treatment part. So it contextually made sense and flowed with the program.

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The other thing that you can do, remember I said it is within the confines of the size of the disk, and if you are talking about web-based, it is within the confines of whatever server you want to put it on, so limitless basically.

But you can really have that library of information, and you can build into it an atlas. Here we talk about within the program, what these lobules are, what the duct is for ductal carcinoma and things of that nature. So you can actually come in and review that kind of information. There are frequently asked questions that you can pull in and actually bring in the bigger question that you may have.

Let me leave this one real quick. I am going to show you one last program, which is known as a Group Lifestyle Balance Program. It is based on the diabetes primary prevention study. What was different is -- if you saw this, this was sort of presentation information, contextual based, but sort of a didactic presentation, somebody presenting information to them.

The diabetes primary prevention study was actually a group session. It was initially one on one,

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and then they migrated it to group sessions where it was counseling. You had a group of people sitting around the table essentially, very similar to this, and they were learning about diabetes and how to prevent it and how to do lifestyle management type things. So it is kind of challenging, how can we take a content like that and turn it into a multimedia-based product that somebody can use on their own.

One of the big challenges also is this desire to provide the one-on-one counseling or the group, that live interaction. So what we did is we actually created our own virtual group. So we cast a group of talented actors and actresses and created a virtual group.

They then go through the content, and as you follow them through the content, you learn as they learn.

They are content presenters, as well as receivers of the information.

The interesting thing about it was during the time that we filmed this -- and this ultimately was 64 hours of video that was cut down to two and a half hours that is contained in here -- by the time we finished that two weeks of filming, the people had become attached to

these characters that had developed.

One of the guys on here whose name is Jeff, they were rooting for him to ask out Laurel, who the nurse was the educator. As we were wrapping up, they said ask her out. Look, guys, this is not a soap opera. Wait for version two maybe.

[Laughter.]

COL MAUFFRAY: So this program is designed to be conducted over three months. There are three disks contained in the product. Each one of them corresponds to that month of education that they are supposed to learn.

It also, though, has that didactic piece that we have talked about earlier that patients do want, what is the anatomy, what happened inside my son or husband's brain when that IED went off, what resulted in this traumatic brain injury, what was the process that caused it.

So that kind of information can be presented like you have seen before, and here we just talk about what is metabolic syndrome which is one of the risk factors with diabetes.

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That is Laurel, by the way.

[Video presentation.]

COL MAUFFRAY: As we developed this particular piece, we created this group, and this is just an introduction to that group. This is just a different way to convey information.

[Video presentation.]

COL MAUFFRAY: This was designed to be broken into weeks and then months. After you finish each one of the segments within a week, you are presented with the ability to take a little knowledge challenge that we have here, a way to sort of reinforce those ideas, and this gets back into that multimedia aspect of it.

As you bring in the knowledge challenge, you have a text-based document, but interactive in that you can submit an answer, get feedback as to whether you were right or wrong.

If you are not really sure, then you are linked directly back into the program exactly where that answer is. So you go, "Oh, I would like to review that real quick." Well, it will actually take you right back to where it was. It tells you what the intent of the

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program is at that point.

The other thing that we did, there is a vast amount of handouts that corresponded to this program. Those are all PDF files. So it makes them also printable and also linked in. Where that information we were just asked about in that question is linked directly into that PDF file, and the patients can print those out and have them in a printed document as well. So there, you are able to provide in a single format, a printed document, as well as a video-based document, text-based documents, and all in a single package for presentation.

The other thing I wanted to show you real quick is there is a guide here for the entire program. We talked about that encyclopedia earlier. You can see how much information is actually here, sort of overwhelming if you just handed it to them from the beginning. So we kind of hide that from them, but if somebody is a multiple user or whatever, they can actually go in and directly access that one little bit of information if they wanted.

The other thing I would like to let you see, we talked about resources, so how can you give them access

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to a lot of different things.

I think one thing that is nice when you talk about all the things that are out there -- and there is a lot that is out there. There are a lot of programs apparently being developed on traumatic brain injury. The Army is developing programs. We are working on this program, but it is nice from a user's standpoint if you feel like what you are getting is a complete package. It is something that was designed and built together and that it all goes together. It has the same look, the same feel, and so it doesn't look like you are sort of piecemealing something together from a lot of different pieces and parts. That this is a complete package.

So, if you look here, you can actually come in.

We determined whether they had metabolic syndrome. You can get BMI calculators anywhere, but it was nice to have one that sort of followed our little field. A heart rate calculator for your target heart rate and a description of how to use it.

Then all those knowledge challenge questions that we talked about before are accessible here in one group. So you can actually pull them all up at one time.

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DR. PRIES: Could I ask you a question, please?

COL MAUFFRAY: Yes, please.

DR. PRIES: Is your game room really interactive health games?

COL MAUFFRAY: Well, I will show you the game room. It is a little different. It is related to this particular program.

So what we did, as we were developing this with some of our nurse educators, what are the kinds of things that are important to patients, what do they actually find useful, and one, of course, is that menu, how do you actually look at a menu and decide what is healthy and what is not.

So what we did is we created a few sample menus, and it just lets you come in and make a few choices and probably choices we all made this morning. Well, if you weren't driving around Washington.

[Laughter.]

COL MAUFFRAY: So it lets you come through and see that that particular choice may not have been the best choice. You have got 532 calories, 31 grams of fat, but then you make a very simple change and just go with

skim milk and fresh fruit, recalculate, all of a sudden you nearly have your calories and you only have a third of the fat. So it just lets you play around. It does not make any judgmental things or anything like that. It just lets you play around with it, and it gives you the idea that, well, it is important what you pick, and you can see some other ones there.

Another one was this one, the comparison. This, again, is not a judgmental thing, what is better for you, but it is just sort of driving home that point.

We all go after that fish sandwich, but, in fact, that is not a very good choice. This Snickers bar over here from a calorie-only standpoint has fewer calories, and that is kind of unsettling when you look at that.

And there are a few others. The same thing, if you don't put the ranch dressing on -- or if you put it on, you have more calories in that, than you have in that big old huge thing of fries, with the caveat describing the fact that we are not suggesting that you eat the candy bar, but these are things to consider.

Then this is the one I always found motivating is these calorie equivalencies. If you ate the Snickers

bar, what does that actually mean? Well, it means a lot.

You have got to actually work that thing off, so 25 minutes of continuous sweating to work off that.

A lot of people said, "Oh. Well, I walked around the mall. I will eat my Snickers bar." It's not doing it. This is not going to work. So there are a number of these in here.

Like I said, I think that is one of the more motivating things to actually see what it is. If you eat that Happy Meal or this combo meal here, well, you better be prepared to work to get rid of it, and just walking in from the parking lot, three spaces further down, doesn't cut it.

Two and a half hours mowing the lawn, that is a big yard if you are going to push a lawn mower around for two and a half hours.

The other thing within this one, same kind of stuff, glossary of terms, so if somebody wanted those medical terms and what do they actually mean, you can dive down into those and drill in as much as you really want.

Again, you are not presenting it to them in

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their face, but if they want it, it is all there.

One other little quick thing is the FAQs here, just presented as a little note pad where maybe you would have scribbled down some stuff, and you can actually go through and get the information, is there actually a cure for diabetes.

For those of us out in Colorado, this is actually important. Our starting quarterback for the Denver Broncos was diagnosed with Type 1 diabetes. So that is a little concerning.

You can also pull up, like this. This is a document unrelated to our particular program, but put out by the CDC, and it tells you how to use a pedometer, which is one of the components of this program. When we package it together and send it out, it actually includes the pedometer for them to use.

All right. The other thing you can do is pull up other websites. So you can make it to where the program is aware that it is online, aware that the computer has a network connection. So you just click on there, and it will haul you off to another site where there is other information with a caveat that whoever

made that science responsible for its content, we are. So we go through, and we try to pick. Normally, it is big organizations, big universities, or the ADA or somebody that has reputable information that we included on sites like that, not individual doctor websites or anything of that nature.

I think that was all I was going to show you on that one. Then you can see there's just a huge number of people that are involved in the development of one of these programs. It is not just something you pull together overnight.

Well, that was what I was going to show you, the programs that we already have in development. I will just set these out and pass them around. You can take a look. If anybody has one they want, you are welcome to keep it, take it or whatever.

That was one of the issues we ran into with our pregnancy program. One of our medical centers didn't realize we actually provided them free of charge, and they were worried how they would buy them. So we have our screen program, which we send out about 16- to 17,000 copies a year of that program.

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The medical center was having a raffle, and so they would have their prenatal visit. The moms, new moms to be would come in, and they would all put their name on a piece of paper, and at the end of the prenatal visit, they would draw one name. One got it, and 19 didn't. So we found out, no, that is not our intent, please. Give all 20 a copy, and we will send you more. So we got that fixed, and the utilization of that program now is at about the same level as number of pregnancies we have in the Air Force every year. So it has pretty well penetrated that market, saturated it, very effective. They love it.

One of the things that I also wanted to point out to you, when you look at the distribution method of a program, obviously, you need to understand what is the technical savvy-ness of the target audience that you are going after, and I would venture to say that a lot of our senior citizens are absolutely capable and very much into computer-based technology. So I wouldn't eliminate any group based on that, but we do try to provide it in the broadest spectrum that we possibly can, all the way from video up through what you see here, which are the

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CD-ROM-based programs, which are the most media-rich, interactive that we have.

The other thing that is important to remember -- and I sort of call it the volatility of the information that you are providing, and by that, I mean how likely is it to change.

So, if what you are doing is you are putting something into a fixed media product and you go and you make 10,000 copies of it and what you put in there changed tomorrow, you now have 10,000 coasters.

That almost happened. One of those programs on hypertension, literally the day we had given the go-ahead to replicate 15,000 copies, the new guideline released on pre-hypertension came out. We were on the phone with the replicator saying, "Stop. We can't let this go," and we had to pull it back in and make some changes to the program, but that is important to remember. If it is video-based, animation-based, and in a fixed format, then if it is something you need to make a change to, it is much harder to make a change.

Web-based is fairly easy. You can upload a new document to a website, no problem.

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What we have done for our programs, for example, the refractive surgery program has a lot of policy and information that is part of it, that is volatile information. The policy has changed probably on a yearly basis.

So what we do is we give a brief description in the program as to what general guidelines are, but the specific policies, we link out to a website that we only maintain, so that that volatile information can live there and be edited and updated very easily. So that is just something to keep in mind as you look at developing something is exactly what it is and how you are going to convey the information.

You talked earlier about a self-assessment, in looking at doing sort of your own needs analysis on a self-assessment plan. One of the programs that we are also working with the University of Pittsburgh on and the American Association of Diabetic Educators is a Type 2 diabetes education program.

What you saw in the group just now is knowledge is prevention. I don't have diabetes. I am at risk. How do I keep from getting it? By the way, that

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particular study showed a 15-percent reduction in the onset of Type 2 diabetes in an at-risk population if they completed that program, so a huge potential.

This other one is Type 2 diabetes, I have it, how do I treat it, sort of self-management. It is being designed in a two-phase piece. One will develop sort of the building blocks that we need to convey the information, all of that content, and the next phase is taking an assessment tool that has been developed and being vetted, and we are trying to shorten it. It is a little long at the moment. So that a patient can sit down, more than likely web-based, provide the self-assessment. Then the program on the fly will assemble the information that they need, not only those areas that they may be lacking in, but also the self-assessment tool makes a determination of what it is that they are receptive to learn about today.

So now you get custom education provided to them at the moment that they sit down at their computer, not only targeting their need, but targeting their desire to learn about a particular topic, but the intelligence of that is all wrapped around the self-assessment tool.

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When you look at that, that has been under development for probably the last five years, that self-assessment tool, to make sure that it works and provides the correct analysis based on the responses.

I don't know that an equivalent for that exists in the TBI world, but that is something that can be done as you look at it, and you can actually create at that point sort of a custom piece of education. That is something that could drive a deliverable out further, or you do like what we are talking about here with the diabetes thing, that it is a staged process. We are going to deliver the first and then add the self-assessment piece to it secondarily.

The program that we're currently working on, on traumatic brain injury, is really -- in a lot of ways, you have the outline out in front of you -- remarkably similar to what you guys have been discussing.

I think the scope of what you are approaching is probably broader than what we have developed there, and part of that is budgetary restriction. I don't think our current outlay for that particular program that we would be looking at trying to incorporate and include

everything that you guys are looking to develop as a curriculum.

But what we thought was very important was making sure that the concept that we were developing at least flowed with and was in sync with what you guys are talking about, so that the message is consistent, and then that there is also the possibility that this is part of a bigger project that ultimately provides all of that content to the health care provider. This can be sort of an initial foundation, and then you build on it. That is just one of the concepts out there.

I know you guys have a long way in going to developing your curriculum, but for us, this was an opportunity, at least right now a window that we have, before we take the printed word and turn it into one of these products to modify, adjust it, and make changes to it, and that window will close in the not too distant future. So we were hoping to make sure that what we had there flowed and was consistent. So any feedback you guys have on that, it certainly is very helpful.

The Center of Excellence has been and has always been dedicated to the patients and their family

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members in providing their education. The programs that we have produced, as you have seen, are not your standard little PowerPoint presentations. They are very high-quality, enterprise-level solutions, and in recognition of that, the CEMM has over the last number of years received about 75 national/international awards, some of which are some of the industry's highest awards, which are called FREDI [ph] awards, for outstanding achievements in a particular area, going up against some of the real big industry giants in the field and winning in those areas.

I have a few minutes, if anybody has any questions. I would certainly be happy to try to answer them, or if Dr. Jaffee had anything in there that I missed in there, sometimes I will jump over something.

COL JAFFEE: Just clarify the services.

COL MAUFFRAY: Right. We are an Air Force organization, and the programs that we produce, we make available to anyone that is a military beneficiary.

For example, our hypertension program, which was making its way around at one point, is one of the tool kit pieces for the DoD/VA clinical practice

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guidelines.

We are currently developing the low back pain education tool for the VA/DoD clinical practice guideline on low back pain.

So, although our budget doesn't allow for us to hand out a particular program to every single member of DoD, it does allow us to make our websites freely available to anybody in DoD or otherwise, and then what we do normally, if we're say placing an order for the hypertension program, we will contact some of our sister services, and they join us. They just pay for the fixed media product. We don't charge them some profit on it or anything. It is what it cost us. We both benefit. When you order in quantity, the overall cost goes down, and we handle the distribution for the Air Force side. They handle the distribution for the Army side.

The future of the CEMM organizationally is one of those things that has been addressed. It is sort of the premier DoD organization which focuses on this, and the question has been raised, as often is the case when you talk about money, it is a great organization, but to grow it, we need to look at tri-service funding levels

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for it.

So the one option was to actually move it to a health affairs-level organization that the Air Force remains the executive agent for, and then everything turns purple for the most part and becomes tri-service. That is an ongoing discussion for that as well, but all of our products are made and used. We ship several thousand a year of our pregnancy program to the Army and thousands of our hypertension programs are shipped to Army and Navy as well.

COL JAFFEE: This is more of a technology question, if I understood from previous interactions. If you are developing a product and want to know how well it works, being able to track the usage, especially on the web-based --

COL MAUFFRAY: Yes. Web-based is very easy to do. Actually, all of our programs have statistical data-gathering programs that monitor the usage. So, at any moment, I can actually log into a particular website, and I know what the bandwidth draw is on it. I can tell how many hits it has got. I can tell how many individual users it gets. I can tell where those users come from as

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far as the domain is concerned, where they are coming from a dot-com, a dot-mil, or dot-edu. So it does provide that kind of functionality very easily. So you can really monitor websites very easily in that regard.

One of the issues that is always out there is if you are going to collect personally identifiable medical data, you enter a world of HIPAA, and that is always a place to be concerned because HIPAA also usually equals lawyers, and you can get yourself into some trouble.

I think an inadvertent disclosure of HIPAA information, there is a \$25,000 fine. It is per exposure. So, if you handed somebody a list, say people with a particular diagnosis and there were 100 people on there, well, you just 100 times 25,000, if it was inadvertent.

If you intentionally handed it to them, it is 250,000 times 100. So you have to be very careful about how you get that information and whether you have permission and securing any kind of medical data that way.

I know in the minutes, they were talking about

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blog-type sites. Those are usually not as big, so long as you are not moderating and putting out their medical information. If they provide it, that is a different story. That is up to them, but if you are providing it and you are storing it where they have access to it --

[Video presentation.]

MS. CAMPBELL-COTLER: Carolyn, why don't you go first.

MS. ROCCHIO: I am going to play devil's advocate here --

COL MAUFFRAY: Sure.

MS. ROCCHIO: -- about content.

COL MAUFFRAY: Please.

MS. ROCCHIO: I question the usage of Judith Faulkner's article here, not that it isn't good. It is a very good article, and I actually have permission to redistribute that article.

This article was written in 1985, and you know, Dr. Faulkner does wonderful work. She very seldom publishes. Most of her articles were done for distribution to State brain injury associations, to then recopy and redistribute.

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I just think there is a lot more updated information that might go in here.

COL MAUFFRAY: And that was one of our script developers that found that and really liked it and put it in as a suggested thing to include in no other format than what you see there in the printed format.

MS. ROCCHIO: I mean, even the article itself shows it is dated by the use of head instead of brain injury.

COL MAUFFRAY: Sure.

MS. ROCCHIO: It is peppered throughout. It does not use people first language, which we adopted in the early 1990s. It constantly refers to "head-injured person" instead of a "person with a brain injury." So that particular article, even though contentwise I always liked her work, I just think it needs an updated article.

COL MAUFFRAY: Sure. Thanks for the feedback. I appreciate it.

Yes, ma'am.

DR. PRIES: I really applaud you for your use of a self-assessment. What kind of a conceptual framework do you use for that? Is it stages of change,

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or do you assess self-efficacy, or how do you do that?

COL MAUFFRAY: The particular one for the diabetes project was developed by several of the behavioralists at the University of Pittsburgh, and it is currently being modified.

It started out as nearly 50 pages of information.

DR. PRIES: Can't do that.

COL MAUFFRAY: That was the first thing I said, it is not going to happen.

DR. PRIES: Yes.

COL MAUFFRAY: So they have been refining it. It is now down to I think about three or four pages of information, which means that every single question, it is critically important that it be answered truthfully, but it does look at a number of those types of behavioral outcomes, and then it also follows the patient looking at -- so there is a self-assessment tool, and then there are reassessment tools that will be followed along later. So you can actually look at where they started and then where they are.

One of the problems we have, though, we have to

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store that information. So that has been one of our barriers is that it will have to go web-based, and we have to store the information because you can't expect them to answer the questions every single time they come to your website.

So not only do we need to store the information, but we also need to store their progress throughout the program, so we can pick up where they left off as well, but it was a very tightly developed assessment tool. Like I said, though, it has been in development for five years at the University of Pittsburgh and with the AADE.

So you look at that kind of development timeline for something like TBI, that is usually problematic.

This is people very dedicated and working that issue as part of their main job. So it really is a daunting task sometimes to make a short, accurate assessment tool.

DR. PRIES: I think you have tried to go there, though.

COL MAUFFRAY: Right.

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Yes, ma'am.

MS. ROCCHIO: I have one more recommendation. When you are talking about the stats, that there is 1.4 million American civilians sustaining brain injuries, I would include the 5.3 million currently living with the disabling effects of brain injury.

COL MAUFFRAY: That is a good point.

MS. ROCCHIO: I think that number kind of puts it in perspective of how large the population really is.

COL MAUFFRAY: That is a good point.

DR. FLYNN: I was going to ask if you have any collaborative efforts with the Center of Excellence Telemedicine TBI/PTSD group.

COL MAUFFRAY: I have not with that particular group. We have a number of collaborative efforts with this particular program with Dr. Jaffee, but have not worked with the telemedicine group.

I have worked with the telemedicine group on an ophthalmology standpoint, but not for this particular one.

One of the challenges is that for a lot of the organizations, there is not a single entity that you can

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touch that is responsible for development of patient education. It is a group that has an interest in, then development something. So you have this stuff spread all over the place. So it certainly could be very beneficial to have a single organization that is able to know what is going on with everyone.

Yes, ma'am.

DR. CAR-BLANCHARD: On these CDs, what is your turnaround time from conceptualization to the end of product?

COL MAUFFRAY: It depends o a number of factors. If you just said in general, starting from scratch, you had an idea, it is about 18 months, and included in that, about a third of that is contracting time for us.

So, with the TBI project, we are currently beyond that, and then we are way beyond the initial development phase. We are further into it.

So, with the TBI project, we are hoping to have that project finished hopefully by the end of this calendar year or at least in an initial working stage by that point.

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Some projects are quicker. The other thing that factors in, as we are finding with some of the other groups, for example, PTSD, how much agreement, how much consensus is there, and if you are trying to build consensus, that is a hard thing to do. So, if you have science that backs up what you are saying, for example, with the BBP project, then that is easy, "Well, the science says," and that is where you go.

When you have ideas and concepts and preferences on how something is treated, but not science to support it, then you get into fights, and that can delay the final outcome.

Yes, ma'am.

MS. ROCCHIO: I have one more nitpicking.

COL MAUFFRAY: No, you are not nitpicking, honestly. We appreciate your input.

MS. ROCCHIO: Under caregiver information, Point No. 54, at the very bottom there, it refers to psychiatric problems that may surface. Are these truly DSN for diagnosis, or are these psychosocial issues that arise? Because even though a certain number of persons with traumatic brain injury may go on to develop a DSN4

diagnosis, they are going to have these problems. They are not necessarily going to be a true psychiatric diagnosis.

COL MAUFFRAY: Have a clinical diagnosis, sure.

MS. ROCCHIO: I just object to that word "psychiatric" there.

COL MAUFFRAY: I think that has already been changed --

MS. ROCCHIO: Good.

COL MAUFFRAY: -- since that particular version.

I think you were looking at Version 6.

MS. ROCCHIO: Yes. It is the one I make my notes on.

COL MAUFFRAY: That's fine. That is the version that was sent out. By the time we actually take them to filming, normally we are looking at a Version 3 or something like that, by the time it is done.

That kind of feedback is very helpful to us.

MS. ROCCHIO: Oh, it's still in here, though.

COL MAUFFRAY: To change it.

COL JAFFEE: One thing you may want to consider

is having the e-mail or point of contact because people might have more of a chance to read more of the materials or offer this type of --

COL MAUFFRAY: Sure, absolutely. I will leave my card here.

Our website and our primary point or interface is very easy: cemm.org. If you go there, there is a link on there that says contact us, and that gets into our office. I will leave cards here as well, and my personal working number on there is as well. Any feedback you guys have certainly would be appreciated it.

Our window to make changes to this is probably measured more in weeks than it is in months. I know you guys are on a longer time frame than that, but certainly if you have any feedback.

The full version of the script, the current electronic version, we can make available to you guys as well. You can send that through DVBIC, and they can send out the entire script. It is about 100 pages currently.

Yes.

MAJ VOGT: Is the actual MACE exam included?

COL MAUFFRAY: We don't include the exam

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itself. Preexposure to it. We just describe it. We just say what it is.

MAJ VOGT: Okay.

COL MAUFFRAY: That came up as well. We didn't want to give people a cheat sheet, as it were, sort of throw off the results.

MAJ VOGT: Okay.

[Laughter.]

COL MAUFFRAY: We just say what it is, so that somebody would know they were being exposed to it.

MS. SARMIENTO: Do you have an estimate of your production costs to do like an individual topic?

COL MAUFFRAY: It varies, depending on the amount of information. For example, the refractive surgery program was something like \$175,000. The group lifestyle balance program was probably closer to three-quarters of a million dollars. There's a lot of factors that go into it to get the final product out there.

You can design a program and say I want a \$50,000 TBI program, and you would get one, or you could say I want a \$50-million TBI program, and you could get

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one of those too. That is one of the things that is hard to get across to contracting people when you are trying to do firm fixed bids and that kind of stuff.

When I say car, you can present the now-discontinued Yugo, or you can present the Lamborgini over here. Somewhere in between is what we are looking for, and how do you put that into words. So we have gone around and around with this contract and how to make those evaluations, how to make sure that what we are getting is what we are intending to get.

The majority of our programs are in that 170 to 350, 500 range, somewhere in there. That's where they go.

Yes, ma'am.

DR. PRIES: In that time frame, do you have an opportunity to do a needs assessment of your target population and pilot it prior to post production?

COL MAUFFRAY: That would be right up Laurie's alley, who just walked away.

[Laughter.]

COL MAUFFRAY: She is a big advocate of the needs assessment.

We are not able to do a full-fledged needs assessment in that kind of time frame, no.

DR. PRIES: Okay.

COL MAUFFRAY: One of the problems in doing it is the cost of then changing everything. When you get to something and you actually say test this, you now have a finished product, for the most part. So then you are redoing the entire product.

What we have been trying to do with the diabetes project, an actual evaluation of the effectiveness of that tool versus the one-on-one session or the group sessions that was the initial basis for the study. So we are looking at that kind of comparison.

The needs assessments, Laurie would be all over those.

Unfortunately, they often sort of run in parallel, and then you get at the end and you go, "Well, it would have been nice to have this little bit of data here beforehand." You would probably add, tack another year on or something, and then you can do it. Another year and double the budget.

COL JAFFEE: So, as far as the needs

assessments, that is one of the reasons why you are here is to get this type of feedback.

COL MAUFFRAY: Absolutely.

COL JAFFEE: With this type of feedback from the panel, I think you will be attending the Town Hall and understand some of the --

COL MAUFFRAY: Oh, yes. We were very interested in the Town Hall portion of it. That kind of information, even though it is not a formal needs assessment, it clearly gives us feedback as to what people are looking for.

I think as you look at what people need as far as a piece of education, as you were talking about, what is it you present, what it is they need is going to change, if you are talking about the acute injury versus somebody who is dealing with a chronic injury. They all need something somewhat different.

A person in the acute injury phase isn't going to be able to look ahead and tell you "I need this," and the person in the chronic phase may not have as clear a vision of what it was they needed initially, that, "Really, I would have loved to have known what the

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anatomy of the brain was, so I knew where that injury had taken place," I would have loved to have known what it meant to these medical terms, where they are really focused on the benefits and the chronic care and that type of thing.

The other thing I just wanted to point out real quickly as well, as you guys move forward, we look at and we are drawn to those severe brain injury patients, and those are the ones that stick out there clearly in our minds.

As we talk about the content that we are providing them and the resources that we are providing their care givers, we are focusing very heavily on those folks, but the end for that is a fairly small number. The very big huge end is this group over here that suffered mild traumatic brain injury and have substantially recovered and appear probably outwardly completely normal, but there is something going on. There are these small things that are happening, behavioral issues, personality, emotional, all these kind of things.

So we don't want to forget that group of people

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that we should provide information not only to the patient and caregiver about how to deal with it, but also how to recognize that this might be what is going on. That you don't realize it, but this is someone who suffered from a brain injury, and here's some things that you need to do to help those people. That is a huge group of patients.

If we just focus on the severely brain-injured folks, these people kind of get left out again.

MS. CAMPBELL-COTLER: Will your product that you are developing include that component?

COL MAUFFRAY: It does cover both. We don't have the resources in there to go really in depth with some of the things you were describing here earlier which were kind of actual skills, teaching-type things. We don't have that in there. That was never a goal of this particular project, but rather to describe some of the things that you may need to do, set expectations as somebody providing care, long-term care, but not telling you necessarily how to do it.

The piece that you had that was sent out that talked about the family caregiver was more that little

bit about what you were touching on earlier, was not being up front and forcing us to take care of ourself, but suggesting that they take care of themselves and some tips on how to do that.

The rest of the program, although not necessarily directly indicated that it is for the caregiver, clearly is information that they all could use. It is that basic anatomy and basic physiology, all the information about recovery and long-term consequences. So it is a lot of information that they all want to know, and they are not necessarily specifically within the outline saying that this is for a caregiver, information that anyone, TBI or interacting with somebody with TBI wants to know. It is sort of one of the general things.

One of the notes we wrote down earlier, it was the behavioral connection that we talked about earlier. So that where the brain injury had occurred, make sure that not only did we talk about what it meant anatomically for that particular part of the brain, our little interactive brain, but what it also meant behaviorally and things of that nature.

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MS. CAMPBELL-COTLER: So thank you for your excellent presentation.

COL MAUFFRAY: Oh, thank you.

MS. CAMPBELL-COTLER: They were just really, really interesting videos that you have developed. It is nice to know they are available on the web for the disability population.

COL MAUFFRAY: Anyone can access them, actually. I will throw these out as well.

We create a number of ways for people to get access to all these kinds of tools, and one of the little things that we developed, if I can find them here -- I may have pulled them out. I will bring them with me tomorrow. They are little cards. They are business-size cards. We call them "web cards." Since we made them up, we can call them whatever we want.

[Laughter.]

COL MAUFFRAY: They are nicely, graphically designed cards, colorful, match whatever the program is, and it has the URL on it. So you can actually hand out the web card, and so you can actually get the patient there that way.

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MS. CAMPBELL-COTLER: Wonderful.

We had talked about as a committee, the various ways in which we wanted to communicate with family caregivers, print media, web-based, multimedia approaches, and we have seen here a very interesting example of a multimedia mechanism. I am wondering what the committee thinks about this and your initial thoughts and responses to how that might fit in with the work that we are doing here.

CAPT HEPPEL: We were just saying how great it was. We like it.

MAJ VOGT: I like it a lot. Yes.

MS. CAMPBELL-COTLER: So, as you are getting closer to development, please stay in touch with us.

COL MAUFFRAY: Sure.

MS. CAMPBELL-COTLER: As we are thinking about modules and we are talking about some of the things that we consider core or basics that we want people to be able to understand, like anatomy and physiology, like some of the things that you will be covering, maybe there is a way in which we can link these things together that is meaningful to the patient.

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COL MAUFFRAY: Absolutely. I sort of had alluded to it earlier. It is nice to have something that looks like it was all built and designed to work together.

MS. CAMPBELL-COTLER: Yes.

COL MAUFFRAY: That way, you don't feel like you are kind of getting a piece here, a piece there, even though you may borrow pieces from someplace. When you redesign and make it fit, I think that is important to do.

One of the discussions that we had had when Dr. Jaffee was out in Colorado was the possibility -- our initial development was to take this particular product in its initial release as a CD-ROM, and then the follow-on development would take it to the web, but then you are sort of locked on.

One possibility is to reverse that, take it to the web first. That then provides the opportunity to expand it, to build it out further. Then once it is completed and you say okay, this is the final, where we are going to go with it, then take that to a CD-ROM. So that is one possibility and one way that it may be a good

way to interact on it and not necessarily double those development costs and incur them twice. Actually lay the foundation and then build it from there.

That is what is so nice about our website. You say here is my basic core. Here is my long-term design.

I don't really have the resources right now or the time to have it all build in, but here is the architectural plan of how it is going to work. So you build it, and then you just add those rooms, those different pieces to the website as you go.

MS. CAMPBELL-COTLER: It sounds like the projects are coming to fruition about the same time, December of 2008, at least in a preliminary phase for us before the testing and everything.

COL MAUFFRAY: Right.

MS. CAMPBELL-COTLER: As we develop the modules and as they become approved and tested and refined, the capacity perhaps to put a module on the web --

COL MAUFFRAY: Right. It would be something that would exist. Sure.

MS. CAMPBELL-COTLER: You could tailor it, so that it looks like a seamless document.

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COL MAUFFRAY: Exactly.

MS. CAMPBELL-COTLER: But the content would come from us in terms of the family caregiver panel in providing families.

COL MAUFFRAY: Exactly. One of the things that would be helpful in that regard, as we look at that outline and that script, it is to make sure that the two coincide in some way.

So, if our outline is too different from what you are proposing, then it would be hard to make them mesh together, but if we are on basically the same concept and what we are talking about is adding, say, a skills module and a behavioral module or something like that to it, just adding to it, then that is much easier to do than saying we are just going to take the basic core over here and build an entirely new site out of it. That is much more involved.

MS. CAMPBELL-COTLER: Okay.

Any other comments?

COL JAFFEE: That sounds like a very interesting strategy, kind of doing the web first, and augmenting these others as we go.

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COL MAUFFRAY: Exactly.

COL JAFFEE: That is an intriguing idea which makes it incumbent to get the best product possible to really ask the committee to take time and they can concentrate and kind of look at the overall script, and we send it out and give you the feedback.

I know you very much want that kind of feedback.

COL MAUFFRAY: Oh, absolutely. No, we are not offended by the feedback. Please give it to us.

I work on people's faces for a living. So we rely on experts, and traumatic brain injury provides the content. We provide the guidance and the look at the feel and the animation and that sort of on-scene technical expertise.

I have become sort of the "I stayed at the Holiday Inn Express last night." We have to reach that level of understanding to manage the program.

[Laughter.]

COL MAUFFRAY: But we never have our degree in neurology or a practicing neurosurgeon or anything of that nature.

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One of the things also to look at, as you look at this script, that we have been wrestling over a lot is the language piece. I mentioned that early on. That is a huge area, especially in this, because the language is very complex, and so providing it in such a way that the patient understands or the family understands what it is -- because they are going to be exposed to the language.

If you don't give it to them, they won't know what it is that the discussion is that they are having. So you have to give it to them.

Yes, ma'am.

DR. PRIES: Just a resource that we may be able to offer you, I am from VA. We have a partnership right now with the Harvard School of Public Health, Health Literacy Program. We are putting together some CEN guidelines for how to make health communications more health literate, and it is in the development stage right now, but I would be happy to share some of the drafts with you now -

COL MAUFFRAY: Sure, that would be great.

DR. PRIES: -- if that would be of assistance.

COL MAUFFRAY: Oh, yes. Any resource like that

is very helpful to us.

It is an evolving field.

DR. PRIES: Yes.

COL MAUFFRAY: When the center was originally started, it was one of the only few in existence. A lot of companies, commercial enterprises, have come and gone. You see the existence of things like Web M.D. and Doctors Online and things of that nature.

One of the primary differences is that what you see here is that our programs are very media-rich, very engaging, and if you go to Web M.D., it is mostly text-based. We sort of liken ours to, if you look at theirs, it is a mile wide and an inch deep. Look at how much content you get. You can find something about almost anything, but you are not going to find a lot about pretty much anything.

Whereas ours, we have a much more limited number of topics that we cover, but we cover them from start to finish and very in depth. So it provides that kind of encyclopedic level of information, but you are only exposed to what you want to see.

Just one other thing, as you look at developing

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something like this, unlike a textbook or a novel that you give somebody and you say you start on page 1 and you are going to read through it, you are going to end on page 299 and you went through it in a completely linear fashion, something like this is totally nonlinear, or if the thing is you say there is a certain core content information, I need a patient or a family member to know, then what you try to do is you can develop an interface such that it guides them, directs them, forces them to make certain decisions, hopefully somewhat not really known to them, that you are directing what they are doing to get them to where you need to go. Then you give them the free access to the rest of the information, but you need them to know this first and then let them have the free access.

It became even more of a fight as the web has become more prominent in this field because if you go on the web, it is a total free-for-all. People are zipping around here and there, all over the place. I will look at the statistics. I just landed on a page for two-tenths of a second. I didn't even load in that amount of time. So there is a lot of that kind of

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movement that takes places.

So, as you look at web developers and program developers, there is this fight that goes on, as you try to control some of these movements, versus them wanting just a free-for-all movement for that site, but that is just something to kind of keep in the back of your mind is there is a certain amount of core content.

One way that we approached it, for example, in the cardio series, which is there is a hypertension version, a CAD version out here, is we had a little 15-to-18-minute intro piece. So it says first-time users, and we called it "Cardio Connection." It was like an investigative newscast.

So you come onto a set, and you have these newscasters who are interviewing patients, interviewing doctors, providing information, but that little first 15 minutes was sort of the basic information we thought everybody needed. So we wanted to make sur they all got that, and then they could go to what we call the "Cardio Handbook."

There, it was just a free-for-all. You go wherever you wanted, and you drill down as deep as you

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wanted about any particular topic. So that is one approach you can go.

When we put out a revision of the program on a DVD format, we kind of allow people to go free-for-all, and they seem to prefer that better.

MS. CAMPBELL-COTLER: Speaking of language, are these available in other languages?

COL MAUFFRAY: Only the pregnancy program is done in Spanish. It is a very costly thing to do, to convert a program to another language. The translation is -- well, it is dependent on how common the language is. So, if you want to go to Spanish, well, it is costly, but not too horrible because a lot of people speak the language.

If you want to pick some obscure dialect of Chinese, then you might have a really, really difficult time and pay a fortune for it.

So that is the only one that we did in another language. We did a survey. We did sort of a little needs assessment in advance, trying to get a feel for it.

Surprising, it may be because our needs assessment was the military, not all of the United

States, and it was luke-warm kind of reception. We went on and did it, and they are all provided that way. The second language isn't every copy. So we are not necessarily able to get feedback of which version is somebody using because they get one version, and they choose the language that they want at that time. So we are not really seeing what the language choice is, but that is the only one.

There was a particular need down in San Antonio where we thought that we could address it, without expending a huge amount of money. We have a decent translation out of it.

That is another problem. My knowledge of medical Spanish is limited to ophthalmic Spanish. So being able to go through and proof it can be challenging. So you get these translations back, and who knows what they really say.

MS. CAMPBELL-COTLER: As we think about family caregivers, though, who may be adults, who are not native speakers of English, I would like to hear from the panel about how that breaks down, what you think is needed.

MS. COLLINS: Well, Puerto Rico has a huge

garden population, and it has been deployed multiple times. So I would think that would be one.

COL MAUFFRAY: So Spanish again.

MS. COLLINS: Yes.

MS. ROCCHIO: And the difference there is they speak Spanish, Spain Spanish, with Cuban dialect. So you have those kinds of differences.

All of our translations in Florida are in Cuban dialect.

COL MAUFFRAY: How much similarity or overlap.

MS. CAMPBELL-COTLER: Is there a need for translation in any other language where we have a significant population?

COL MAUFFRAY: Korean was another one that always came up to us, but as we looked at it -- because we have people based there who get married, but when you looked at it as an overall percentage, it was relatively small. It was one that was often requested.

MS. CAMPBELL-COTLER: All right.

Do we have demographics on the regional cultural background of individuals who experienced TBI? Do we have that breakdown?

COL JAFFEE: I think we do.

MS. CAMPBELL-COTLER: That might guide us.

MR. DODSON: We were running into a lot of Mexican Spanish, primarily Southern California, Arizona, New Mexico, and even down below.

MS. CAMPBELL-COTLER: So we definitely need to consider a translation to Spanish for the family caregivers and then other languages as we assess the need.

The service member speaks English, but the family around that service member may not.

MR. DODSON: And the service member is not always that clear by the time we get them. We are getting them probably 12 days after the incident.

MS. CAMPBELL-COTLER: Well, I thank you very much.

COL MAUFFRAY: Thank you. Appreciate it.

MS. CAMPBELL-COTLER: We look forward to being in touch, and we will get the 100-page copy of the script.

COL MAUFFRAY: Sure. Enjoy the reading.

[Laughter.]

COL MAUFFRAY: The initial part, it is still undergoing revision, but the initial anatomy portion is probably some of the most challenging to get through. That is the part of where we really looked at what is the different way to present this, and that is what we are looking at, the interactive approach. So that is changing as well, ultimately.

Like I said, we are at Version 1.6. We will probably reach Version 3 by the time we are done.

MS. CAMPBELL-COTLER: Thank you.

COL MAUFFRAY: Thank you very much. I appreciate your time.

[Applause.]

MS. CAMPBELL-COTLER: If anyone has any interest in speaking with our guests individually, please do.

COL MAUFFRAY: Absolutely. Any feedback, if anybody feels ambitious tonight, wants the whole script, I have it.

Selection of Curriculum Modules

MS. CAMPBELL-COTLER: We are going to be up until 9 o'clock tonight listening to testimony.

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Well, thank you so much.

We have a break scheduled at 3:00. So we have a half an hour to just kind of get ourselves organized for the next piece.

I just want to reconfirm the modules that we have agreed on earlier before lunch and see if there are any others we need to add or if there is any more consolidation that we need to do. Then the plan will be to break into small groups. People can self-select into a particular module or group, or we may have to put more than one module in a group, depending upon the numbers we have. Then after break, we will just go into the corners of the room and work out specifics in terms of what we want to see in the content there under the module.

Some of that work has already been done, as was pointed out, but we will refine it even further and keep moving.

Just to go back to what we agreed on, we are not going to focus so much on the info on TBI 101, but that piece, that is pretty much boilerplate. We will delegate that to DVBIC to put together, and certainly, you will have lots of opportunity to review and comment

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on that.

We want to talk about a module on behavioral management, a module on cognition, a module on communications, a module on -- let's call this psychological health, which would include PTSD and depression.

I am just having another idea about how we might go about our work on this. Let's shorten our time in a small group and go about this. We have a modular on the behavioral needs or behavioral management and other kind of management needs with regard to the service member who has the TBI.

Then we have the whole series of caregiver needs, and then we talked about systems management.

So those are three large headings under which we have modules, and I am thinking that perhaps what we should do is break into small groups around these modules, get those fleshed out in about 45 minutes, then move on to the systems modules and then to the caregiver needs modules. Does that make sense?

MS. ROCCHIO: Well, actually, cognition and behavior really goes together. One drives the other.

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MS. CAMPBELL-COTLER: Another way to approach this and to take a longer period of time would be to break into three groups, one having to do with the behavioral modules, one having to do with the caregiver need modules, and the other having to do with the systems management modules. Maybe that is a better approach, three large groups, three work groups, each addressing one of the broader headings.

Does that make sense to people?

MS. MOESSNER: What were those again?

MS. CAMPBELL-COTLER: The behavior management which is a broad term for mental health, cognition, communication, behavior. Then we have the systems management, and then third would be the caregiver needs module.

MS. MOESSNER: I think I am getting confused, only confused because I think the one that is called behavior management, I think if it was just a residual, like TBI residuals, that kind of -- you know, so that you are really trying to describe what other kind of residuals or possible residuals and related interventions.

MR. DODSON: Effects.

MS. MOESSNER: The effects, yes, whatever you want to call it. Yes. Maybe that is one. Then that sorts a little bit better in my mind. I'm not sure.

MS. CAMPBELL-COTLER: Then the systems management and then the caregiver needs. Those are broad frameworks under which there will be modules that we discussed and outlined earlier and even more in terms of content within those modules.

MS. MOESSNER: We will give it a try. This is a great time.

MS. CAMPBELL-COTLER: Right. No, it is only 2:30.

MS. MOESSNER: I know.

MS. CAMPBELL-COTLER: We could use a break right now, couldn't we?

MS. MOESSNER: Maybe just a little stretch and think about it a minute.

MS. CAMPBELL-COTLER: Why don't we do that. Then, as we form groups, you can go pick up a refreshment, bring it to your area, and have a refreshment as it comes into the room around 3 o'clock,

but it sounds like everybody would like a little break at this moment. So why don't we take one for 15 minutes, and we can meet at a quarter to 3:00.

MS. MOESSNER: Sure. Sounds good.

[Break.]

Content Development of Modules

MS. CAMPBELL-COTLER: I just wanted to go over a couple of things before we break into our small group discussions, mostly about tonight at the Town Hall meeting.

I just wanted to let you know what some of the procedures are for tonight, so everybody knows what is happening.

We are going to have a staff person in the room where the Town Hall is going to be held, and that person will be there at 5 p.m., just in case we have some early arrivers.

We are going to have two sets of sign-in sheets. One will be for family caregivers, the other for professionals, and people who indicated they planned to speak or not. We asked family caregivers to speak first, and then professional groups.

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We hope we can limit the presentations to five minutes, but we also want to be respectful of what people are saying. So we will try to modulate that a bit. A lot also will depend on how many people we have who want to speak and how much time we have.

We will have the panel chair and the designated Federal officer present, and the panel members are free to sit anywhere in the room that they would like. You can sit in the front, or you can scatter yourselves about, however you are comfortable, but our chair will recognize each of you. You can stand, so that those in the audience know who are the panel members who are here to listen.

The Town Hall meeting will be broadcast via web through an AT&T television connection, and the camera will be fixed, so that it will capture the head table where our panel chair and designated Federal officer will sit and the microphone where the presenters will speak.

Those who are viewing from their laptop or computer around the country will have an opportunity to type in questions as the conference is going on.

This will not be live interactive, though. So

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we will capture those responses tomorrow. I don't know if we will have that information for you before you leave here tomorrow, but we certainly will get it out to you.

In addition to the live web, there will also be three other ways in which people can respond, and that will be through the 1-800 DVBIC number through e-mailing or by sending a letter to our office. That information is going to be posted side by side with the video picture on the web. So that folks will have ample opportunity to write down that content information while they are watching the proceedings.

Yes.

COL MAUFFRAY: What is the web access address?

MS. CAMPBELL-COTLER: Colonel Jaffee?

COL JAFFEE: A DoD facilitator as well.

MS. CAMPBELL-COTLER: Yes, thank you. We will have a facilitator from the Department of Defense coming for the Town Hall meeting, and that will keep us on time and also enable us to engage in any kind of interactive discussion that seems appropriate based on the size of the audience and those who are interested in speaking.

MR. WELSH: What kind of size are you expecting

for the turnout?

MS. CAMPBELL-COTLER: We have the room for between 100 and 150 people. I don't know if we will have that number. There certainly has been a lot of interest around the professional community and the Town Hall meeting. We have done everything we can to reach out to family caregivers, but I just don't know if we are going to have people there or not.

MR. WELSH: Are we using this room tonight?

MS. CAMPBELL-COTLER: No. It will be another room, set up amphitheater style.

COL MAUFFRAY: Is there any login information they need to access it on the web or just go to that site?

MS. CAMPBELL-COTLER: Just go to that site, right.

Okay. Recognizing that there isn't much time between our 5 o'clock meeting closure and the 6 p.m. start time for the Town Hall meeting, we are going to have some hors d'oeuvres available for you at about 5 o'clock, so that you can nourish yourselves before going on to the next event. It is a long day, and I appreciate

your active participation and involvement throughout all of it.

What we are going to do now -- I am sorry for using the microphone. I won't do that much longer. We are going to break into three discussion groups.

One group will focus on the effects of TBI and the interaction of those effects with the family caregiver.

The second group will focus on systems management.

The third group will focus on the needs of the family caregiver.

We have put together the list of ideas that came out of this morning's discussion. So you will have that with you in your small group discussion.

I would like to spend about a half an hour and would ask that you appoint someone to be a recorder, who can report out when we reconvene again.

The goal is not to write the curriculum or not to write the content, but to make sure that we have covered all the topics that need to be part of that module or that module, for example, on cognition which is

in the broad framework of the effects, that what are the high points under cognition that we need to be sure to include in the curriculum as it is written.

Are there any questions about that?

[No response.]

MS. CAMPBELL-COTLER: Okay. Why don't we have the effects group meet over here and the system group meet over here and the family caregiver needs group meet in the back. We will give you the sheets from this morning's discussion.

[Breakout for Small Group Discussions.]

Report Out of Content Development of Modules

MS. CAMPBELL-COTLER: If everyone wouldn't mind taking their seat one more time. We are going to try to wrap up in 15 minutes.

It sounds like what we would like to do is have a representative from each group just spend about five minutes reviewing what you came up with within your group, and then we will dismiss for the day.

Any volunteers for the first group? Anybody who was working in the back, or do you want to do them up here at the mic? Does the mic work?

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MS. MOESSNER: Our discussion centered on the effects of traumatic brain injury, and we looked at developing modules around physical effects first. I am not sure if I am going to go over and list all of these for you, but basically, the pain syndromes, headaches, any of the musculoskeletal conditions that are common, seizures, changes in appetite, body temperature, sensory changes, coordination/balance changes, that sort of thing, sexual dysfunction, neglect syndromes, minimally conscious states, bowel and bladder condition changes. I think those were the big categories that we came up with.

I am not sure how this will play out, if these will all be typed up and sent out to people to make sure, or if you want to comment as we are going through here. I don't know how much time we want to take.

MS. CAMPBELL-COTLER: I think that we will just go through it.

There will be a transcript of all the proceedings. So we will give that out.

MS. MOESSNER: So, if you see anything glaring, you can certainly let us know, but that seems like a fairly comprehensive list.

In terms of cognitive effects, memory, attention, concentration, organization, the executive dysfunction, problem solving, decision-making, cognitive flexibility, the ability to plan again, again, some visual spatial and other neglect syndromes, you will hear some crossover between categories because it is hard to cleanly put in certain possible residuals in particular categories, but you will see a little replication here.

Perseveration, confabulation, perception, speed of processing, and certainly confusion, disorientation. That happens more in the acute side of things.

Then moving on to language, communication, again, we sort of grouped things into social pragmatic communication changes and then also the motor speech changes, you know, ranging from, again, difficulty of making no speech whatsoever, monotone changes, topic selection, perseveration, interrupting, swearing, you know, those things that may interfere with someone communicating with those around him in an effective manner, naming, word finding. We thought these were fairly common situations we see in folks.

Then the longest list we came up with were sort

of neuro, behavioral and emotional sequelae, and so this is a fairly comprehensive list we think, again, from more apathetic conditions and situations to disinhibition and pulsivity, aggressive, anger management issues, lack of awareness, judgment, depression, anxiety, PTSD, suicide, boundary issues, lack of motivation, inconsistency, distractibility, overstimulation problems, hypo/hyper sexuality.

We put a little in here about safety, you know, poor judgment, leading to people being unsafe, loss of social tactfulness. We thought that was a nice way to put it, and compulsive eating, anorexia, substance abuse, dependent behaviors, denial. I think we had a fairly comprehensive list in the neuro behavioral domain.

Then we weren't sure how to categorize the rest of the ideas that were floating around in our group, but there were -- I think we called them "future planning," sort of long-term psychosocial and other situations. I think it was planning for the future, but quality of life.

We weren't sure if anybody else would be addressing some of these areas, but driving, housing,

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transportation, rebuilding relationships, role changes, school work, parenting, recovery expectations, leisure activities, coping, grieving, adjustment issues, self-esteem, medications, legal issues, criminal issues, that TBI is often described as an invisible injury, spirituality, so activities of daily living issues which would be perhaps situations that a family would have to deal with in terms of grocery shopping, bill paying, managing life, and again, those activities of daily living.

Safety was brought up another time. Timeline issues, how recoveries individualize from one person to the next. So, again, this was sort of a broader category. I am not quite sure how that will be put into a module. If you have other ways of describing these issues, please let us know.

MS. CAMPBELL-COTLER: Great.

MS. MOESSNER: Questions?

DR. FLYNN: Just one of the things that I wanted to bring up there, Anne, too was the emphasis that we placed on the impact of TBI on the person's occupational status.

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Some people, because of their occupation, wouldn't be able to return to work, even after a mild traumatic brain injury.

MS. MOESSNER: Right.

DR. FLYNN: And others could after a moderate to severe, depending on how much recovery they have.

MS. MOESSNER: Yes.

Several times, we found ourselves saying this needs to be in the introduction, some of these concepts in the introductory materials that you all are putting together, with some assist, I assume. So we tried to indicate that in a few spots, that it would be nice to get this into the setup material that you are providing.

Okay, thank you.

MS. CAMPBELL-COTLER: Good. Caregiver needs group.

DR. BENEDICT: Recognizing that this list might get altered significantly tonight after tonight's meeting or at least filled in some more, we broke this up into five main topics, the first one being legal and financial, things like guardianship, power of attorney, med power of attorney, planning for the future and all

the sort of things that go along with that, things like advanced directives.

The second category, benefits and entitlements, including things like grants, insurance, scholarships, home modifications, assisted devices, home health care, respite care.

When we were talking about these issues, they are very intertwined. So we could have put them under several of these categories.

The third big category was advocacy, and actually, what we have under here is how to -- dot, dot, dot -- be an advocate and resources like support groups, like Wounded Warrior and Brain Injury Association.

The fourth category was emotional support, things like respite, faith-based groups, community-based groups, counseling, individual, family, child counseling, coping and that idea of the opting-out plan, ways to cope and what to do if you can't, loss in intimacy which I think is a big topic that sometimes is the pink elephant in the room.

The fifth category was self-care and wellness, so addressing healthy behavioral lifestyle practices,

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diet, exercise, sleep, hygiene, smoking, alcohol use, and medications, use of medications, appropriate use of medication.

Routine medical care for yourself, so taking care of yourself and making sure that you are getting your physicals, even going to the doctor in a timely manner when things come up, and then mental health interventions.

Then the last category was family education. This whole thing is about family education, but in particular, we wanted to make sure that we touched on developmental needs of younger and older care givers, just the idea of transitions throughout the phases of recovery and community reintegration, addressing things like comorbidities, particularly like PTSD and substance abuse and mental health issues.

Then this sort of catch-all phrase that we came up with, "information management" and how best to do that, all the information that they are bombarded with and that they don't quite know how to organize or manage.

So we will wait to see what tonight brings, and

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we can probably add some more things to this.

MS. CAMPBELL-COTLER: Thank you. That was wonderful.

Should I speak for the systems group?

[No response.]

MS. CAMPBELL-COTLER: One of the things that was clear as we were going through the system needs, the management of the system needs that family caregivers had was that we found it very difficult to categorize the kind of information that families needed and at what time they needed it. Therefore, I could only imagine how difficult it is for families when this group of professionals really had a difficult time looking at what are the system information needs.

Certainly, the ability to advocate, we have heard that come out of caregiver needs as well, that real training on how to be a self-advocate as well as a patient advocate is a critical need for being able to negotiate the system.

We grappled with a lot of different approaches to this and came down on -- because they were talking about multiple systems of care, the military, training

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facilities, the VA system, if they select private care. So it was very difficult to kind of come up with any one grid that would work for all.

But what we decided after much conversation was that there were four types of people that the family caregivers need to know about and meet and know what kind of information they can expect to receive from that person, case managers, social workers, service liaisons, and the medical team.

So we went through and determined and identified the kind of information that you would seek from each of these service providers. For example, the case manager can help you with priority, the scheduling of appointments. They can get you into doctor's appointments that you might not be able to get into for months without their help from the inside.

They will manage the treatment schedule. So they will let you know as a family caregiver what is coming up this week for your loved one, what particular evaluation, where they need to go, when they need to be there.

There was a lot of discussion about the need to

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really establish a partnership and a dialogue, and perhaps the care manager is a place for this to begin, with a lot of openness about what the family needs and I guess an attitude of helpfulness between the caring professionals towards the families.

We talked about going to the case manager for family caregiver support and counseling and coping skills, directions to either helping that person personally with those issues or getting them to the proper resource within the military structure or the VA structure, options for rehab, that they understand that there is the VA option, but there's also private options and understanding maybe what the various VA hospitals have to offer in terms of rehab.

In the VA system, the case manager and the social worker may be the same, and for the social worker, we felt that that person, you would go to for community resources, for information about home modification, for help with understanding the impact on the family of the TPI, for information about benefits such as food stamps, medicare, TBI and any waivers in various States, that young people who sustain a TBI before age 21 are eligible

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for DD benefits. So social workers are the folks that you would turn to for that information.

The military liaisons are critical people. They need to know where the service member -- on the outpatient basis, they need to know where the service member is in the system at all times.

They provide family assistance and advocacy for travel, lodging, finances, transportation, provide copies of the medical record.

Apparently, with some new laws that have come out, there are some checklists that military liaisons will need to follow or are following. If we get a copy of some of those checklists, we can be sure that the family knows that this is the person to ask about that particular issue.

On the medical team, the various components of that team -- and we just listed a few, the TBI clinic, rehab, speech pathology, but there are many more. So the family understands that there is a multidisciplinary approach, that they should have a copy of their plan of care. That when there are family conferences, that they are very important, and that the family can influence the

course of treatment for their loved one by their advocacy and presence in the family conference, and that we really need to include in the curriculum some information that will help families understand the importance of this conference and the role they play in it.

Again, the medical team will determine when the med board process is started, if it is started.

Colonel Gibson, do you know if we are going to be hearing from the Wounded Warrior program tomorrow?

COL GIBSON: I had Mike Jaffee check in to see whether we can get them over here. If we can, we will provide a briefing. If not, we will do it at the next meeting or by teleconference.

If your folks work with my folks, we can actually do a webcast, a webinar.

MS. CAMPBELL-COTLER: Webinar. Okay.

COL GIBSON: And with the members of the board here. So we will work something.

MS. CAMPBELL-COTLER: Okay.

COL GIBSON: I know I can't provide a briefing on the disability system reengineering. That person is in San Antonio right now. So I can't make that happen.

We may be able to make the Wounded Warrior thing. I don't know what Mike had accomplished.

Yes, Carolyn.

MS. ROCCHIO: Meg, can I point out one thing?

MS. CAMPBELL-COTLER: Yes.

MS. ROCCHIO: Service to developmental disability.

MS. CAMPBELL-COTLER: Yes.

MS. ROCCHIO: Although they are eligible to age 21, the onset of disability must occur before the age of 18.

MS. CAMPBELL-COTLER: Thank you.

MS. ROCCHIO: So they are not going to be eligible for DD services.

MS. CAMPBELL-COTLER: Okay. So the onset has to occur before age 18, and they are eligible up to 21?

MS. ROCCHIO: That is correct.

MS. CAMPBELL-COTLER: Okay. Thank you for clarifying that.

Yes.

DR. BENEDICT: Just a minor thing. You said multidisciplinary approach. It is really more an

interdisciplinary approach, multidisciplinary meaning lots of disciplines maybe not interacting with each other, but in this case, they are. So I think just in terms of wordsmithing, it is more interdisciplinary.

MS. CAMPBELL-COTLER: Terrific.

Interdisciplinary approach. Great.

MS. ROCCHIO: DD also has an IQ threshold that many people with brain injuries will not make.

MS. CAMPBELL-COTLER: Okay. So we may just strike that piece.

Yes.

DR. FLYNN: When soldiers first come into the service, are they informed about particular life insurance companies that don't have combat clauses that would exclude them from any life insurance benefits? That may be a real instructive educational piece if there are insurance companies out there that do not have a combat clause associated with life insurance policies or with disability insurance policies. A lot of them do, but certain ones don't.

COL GIBSON: Can I add to that?

DR. FLYNN: Sure.

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MS. CAMPBELL-COTLER: Yes.

COL GIBSON: My service member colleagues can add as well.

The armed services offer for active-duty folks a very generous, cheap term life insurance program for several hundreds of thousands of dollars.

If a person is disabled, has some sort of disability, the VA offers a similar type of insurance. No qualifications, no medical history qualifications, no exclusions. It is not quite as cheap as it is when you are on active duty, but it is still much more reasonable than buying insurance on the outside.

So point well taken, and they get briefed on this whole insurance thing.

DR. FLYNN: That is for the SGLI?

COL GIBSON: SGLI and VGLI. The issue is in particular with reservists, leave, come back, leave, come back, and how that may interface with private life insurance or health insurance.

MR. DODSON: To answer your basic question, they are not told what insurance companies don't cover, to answer that question, and the issue on SGLI is they

have to sign up for that. It is really bad when somebody didn't sign up for that for some reason and they get here and now they are ineligible for TSGLI.

COL GIBSON: Although I would say the folks that outprocess that are deployers are pretty good about making sure if you are going to deploy and be in harm's way, that they get an opportunity to sign.

MR. DODSON: Okay. I know the National Guard does a real good job at the armories. They are just absolutely saying, "You are signing up. Sign here."

COL GIBSON: Yes, exactly. It is not mandatory. We don't twist anybody's arm.

CDR MILLER: I don't know anybody that has not signed up.

MS. CAMPBELL-COTLER: I do feel that there is a lot more work that we need to do on the systems management piece, and maybe as we get more educated about how the system currently works, which I really am not that knowledgeable about myself, that we can begin to see what is the kind of information that families need to know.

One of the examples that came up was that

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family caregivers need to know about the Family Medical Leave Act, that if they need to be away from their work, that they should really know that they are protected. So that is an example of something. It needs a lot more fleshing out.

Okay. Well, if there are no other comments, then I would say that we are adjourned for this afternoon. We have some hors d'oeuvres and refreshments, so that you might be sustained before we go into the Town Hall meeting, and the Town Hall meeting will start at 6 p.m. It is in the Chesapeake Room.

Thanks, everybody. I think we have had a real productive day, and I want to thank you for your participation.

[Meeting adjourned at 4:50 p.m.]

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