

Brain Injury Commission

Meeting Minutes
September 10, 2019
10:00 a.m. – 12:00 p.m.

Date of meeting: September 10, 2019

Start time: 10:18 a.m.

End time: 12:03 p.m.

Location: Massachusetts State House, Room 428, Boston, MA 02133

Members present (sorted by last name):

Dorothee Alsentzer - *for Dan Tsai, Assistant Secretary, MassHealth*
Rep. Gerard Cassidy – *MA House of Representatives*
Senator Harriette Chandler – *Massachusetts State Senate*
Rep. Kimberly Ferguson – *MA House of Representatives*
Nicole Godaire – *Executive Director, BIA-MA*
Dr. Swathi Kiran – *Boston University*
Josh Mendelsohn - *on behalf of Toni Wolf Commissioner, MA Rehabilitation Commission*
Adelaide Osborne – *MA Rehabilitation Commission*
Helene Robillard – *Brain Injury Survivor*
Yves Singletary – *Department of Public Health*
Secretary Francisco Ureña – *Department of Veteran Services*
Marilyn Price Spivack – *Family Member, Founder of BIAA& BIA-MA, Spaulding Rehabilitation Hospital*

Members absent:

Beth Adams – *Massachusetts General Hospital*
Dr. Imioele Aisiku – *Brigham and Women's Hospital*
Carole Malone – *Assistant Secretary, Office of Elder Affairs*
Undersecretary Lauren Peters – *Executive Office of Health and Human Services*
Senator Dean A. Tran – *Massachusetts State Senate*
Dr. David K. Urion - *Boston Children's Hospital*

Proceedings

The meeting was officially called to order at 10:18am as Representative Ferguson requested a motion to approve the minutes from the July 19 meeting. Representative Cassidy presented the motion. Ms. Godaire requested that the minutes be changed at the top of page 3 to reflect that the commission would like to hear a presentation on solely the SHIP application process. Ms. Robillard abstained from the vote, as she was unable to hear well through the conference line. A unanimous voice vote approved the minutes as amended

Representative Ferguson announced that there was a slight change in the agenda for the meeting. Ms. Adams and Mr. Johnson were unable to present due to personal reasons, but will be presenting at the October meeting. Representative Ferguson opened the floor for discussion of the regional listening sessions. Ms. Godaire reviewed the four sessions that have been held: Brockton and Gloucester in July, Pittsfield and Worcester in August. She lamented that the Representatives and Senators were unable to attend the Gloucester session as they were voting on the budget.

Ms. Godaire invited Ms. Spivack, who attended all of the listening sessions, to share her thoughts. Ms. Spivack believes that the listening sessions reinforced what has been said many times, that people living in rural areas do not have easy access to services. Transportation is also a major issue. Ms. Spivack talked to her colleagues at Spaulding regarding future plans and to see if Spaulding would be interested in expanding into rural areas. While there is interest, again, transportation is a major issue. There is concern that patients will schedule appointments but will not show up

due to lack of transportation, which is very costly to the provider. Another issue Ms. Spivack observed through the listening sessions is the lack of long-term case management. The only people who have long-term case managers are military and those through workman's compensation. Ms. Spivack believes these two issues are important to focus on as the commission forms an agenda going forward.

Ms. Robillard stated that she is concerned with the lack of education on brain injuries evident in primary care physicians and medical personnel in emergency rooms. She would like to see continuing education units about brain injuries made available to medical professionals. As a brain injury survivor herself, she expressed her disappointment that no one explained anything to her and she had to find information on her own. Ms. Spivack agreed and said that it is startling the only professional education available is a one-day meeting hosted by the Brain Injury Association. While it is great that it is available, it needs to be offered continually and there needs to be more on-site training opportunities.

Ms. Godaire asked Secretary Ureña to share his thoughts on the regional listening sessions. Secretary Ureña stated he believed the listening sessions were very heartfelt and that people really just wanted to know that we were listening. He heard a lot of frustration from people throughout the Commonwealth. While he wishes that more veterans participated he felt that if there was a problem we would hear it and it demonstrates that the VA is effectively treating patients. He stated that 70% of doctors do training of some sort at VAs and that the third tier of services the VA provides is research. Senator Chandler asked how to access the research and Secretary Ureña suggested bringing in more presenters through the commission.

Ms. Osborne stated that at one point MassRehab had a federal grant that identified veterans with brain injuries. Part of the program included testing to make sure they fit the criteria and many veterans didn't know that they had a brain injury, but were having trouble living their daily lives. She stated that the yearlong grant was very well funded and staffed and it would great to have again. One point that she took away from the listening session was to reinforce the need to have information readily available in emergency rooms so that people know resources are available.

Dr. Kiran stated that she was also very surprised about the lack of continuum of care. There is no point A to point B and it seemed often times things broke down half way. She would be happy to participate in any modules of learning. Dr. Kiran believes that one-day conferences are great, but webinars would be an effective method of learning as well.

Ms. Godaire stressed the importance of remembering while writing the commission's report that these are people. Our most important question should be, "how do we make their lives better". She believes that the most effective report is a report that shows we are empathetic.

Senator Chandler broached the subject of having a listening session on Cape Cod. Representative Ferguson agreed that while the Cape may be difficult to get to, the commission doesn't want to exclude an entire population. Senator Chandler reflected on the reactions of the members of the public who came to the Pittsfield listening session. She believed they felt neglected and that those who live on the Cape may have similar reactions, thus the commission should host a listening session there. Secretary Ureña agreed that it is important to hold a listening session down the Cape and suggested that the islands are taken into account while planning. Both the ferry schedule and convenient locations must be considered. Representative Ferguson suggested Hyannis.

Representative Cassidy expressed his amazement of the New Start Brain Injury Community Center in Worcester and his desire for more like it throughout the Commonwealth. Senator Chandler stated that ten years ago it was decided there was a need for at least five in the state, but there is still only one. Ms. Godaire stated that the funding for the program comes from the MassRehab Commission and that it is the only program around that is inclusive of all brain injuries.

Senator Chandler suggested that the commission collect all of the pieces of information available to see what is there, what works and what is missing. Ms. Godaire volunteered herself and Ms. Spivack to work on collecting the information. Ms. Spivack suggested a presentation of Blue Cross Blue Shield, Harvard Pilgrim, and a representative from workman's compensation. Representative Ferguson assured her that the intent is to have an insurance panel

present at the November meeting. Ms. Godaire listed the ideal panelists: a representative from private insurance, workman's compensation, MassHealth, the Insurance Commission and TriCare.

Secretary Ureña introduced the presenters, Regina McGlinchey, PhD and Walter Musto, CMSgt (RET) RING. Dr. McGlinchey thanked the commission for the opportunity to present a small sliver of their research thus far and began by providing background information on the program. They are funded by the VA wing of rehabilitation and were originally funded as a TBI Center for Excellence. Shortly thereafter it became clear that was too narrow of a focus. She continued that mild traumatic brain injury is the most common sustained and blasts and blasts explosions cause 75%. They have discovered that one of the biggest problems is exposure to blasts. Dr. McGlinchey urged members to take into context the psychological damage of the blasts and stated that there is data to support a synergy between the physical and psychological damages. Dr. McGlinchey pointed to charts in her presentation that showed the overall trends of both post-traumatic stress disorder (PTSD) and traumatic brain injury (TBI) grew at the same rate between 2000 and 2012, highlighting the parallel between physical and psychological trauma. Senator Chandler questioned why the data stopped in 2012 and if it was dropping at that point. Dr. McGlinchey responded that although she had not updated the chart, that the trend continued upwards in 2018. Mr. Mendelsohn noted that the chart startled him when he reviewed the presentation before the meeting, specifically because so much attention is given to PTSD. Dr. McGlinchey handed it over to her co-presenter Mr. Musto.

Mr. Musto introduced himself as the recruitment specialist and provided his background: he had over 30 years in the military and continued to work with first responders and veterans when he retired in 2006. He stressed the importance of his job focusing on personal relationships, that people don't want to leave voicemails; they want someone to talk to. He began explaining the longitudinal cohort study and the need to see how TBIs affect veterans as they age. They offer three testing dates a week and since March 2010 those dates have been completely filled months in advance, which demonstrates the dire need. After a 2012 cover story by USA Today the study has been receiving calls from veterans across the nation. These veterans pay for their own transportation to the study and more than 60% of them return for evaluation. The TBI is assessed during three time periods: pre-military, military and post military, and severity is assessed according to the DOD Criteria. It was discovered that many veterans had TBIs pre-deployment. Representative Ferguson questioned if there was a typical cause of these pre-military brain injuries. Dr. McGlinchey responded that they were typically childhood injuries. Dr. McGlinchey noted that the most important point in the presentation is that only 8% of the veterans tested have had a TBI and nothing else (i.e. psychological disorders). However, the research shows that if you have a brain injury it is a marker and there is comorbidity with other psychological illnesses such as PTSD and depression. The overall conclusion of the research shows that when TBI exists with other conditions it causes long-term effects. Mr. Musto provides anecdotal stories of veterans he has worked with. Veterans struggle with self-medication using both alcohol and prescription drugs. Through this study he has seen them committed to finding out more about themselves, but it is a very difficult thing to do.

Dr. McGlinchey noted that they are working on a rehabilitation piece and have adapted StepHome using similar concepts. It has received full funding from the VA, but they are still in the pilot phase. Senator Chandler asked how people hear about their program and Dr. McGlinchey responded that it is mostly word of mouth. Senator Chandler asked how the commission and legislature might help them. Dr. McGlinchey responded that she would love to find a way to collaborate as veterans need immersion and help for many issues all at once. She stressed that if multiple sources are conducting research it is important to harmonize, so that there is not just a data dump. Dr. Kiran asked if they would consider applying this research to civilians with brain injuries and PTSD, but not from blasts. Dr. McGlinchey agreed that it could be a useful application, but warned the blast is a whole different mechanism which affects the entire brain, which makes it more complicated than a strong bump on the head.

Ms. Osborne asked how they plan service delivery for different people. Dr. McGlinchey responded that they would begin looking at that once they receive data from the longitudinal study and can see the trajectory. Ms. Godaire noted that BIA-MA is working with Brandeis on a cost medical analysis on the costs of providing cognitive rehabilitation early after a brain injury. Representative Ferguson asked Dr. McGlinchey of the people they see, understanding that they are not a treatment center, how many of them do they give a list of places to go for treatment. Dr. McGlinchey assured Representative Ferguson that they provide this information to all participants. Secretary Ureña asked if they work with the HomeBase program at all. Dr. McGlinchey answered that while they don't formally have a relationship,

some of the study participants go to HomeBase, so they share testing data. Secretary Ureña wondered if there is a mechanism to build a relationship between the two. Senator Chandler asked if their funding has increased or decreased over the years. Dr. McGlinchey stated that the funding began at \$1,000,000 a year and had decreased to \$900,000 but this year it is back to \$1,000,000. Representative Ferguson encouraged all the members to attend the listening session at 2:00 in the House Members Lounge and thanked the presenters for coming. At 12:03pm Representative Cassidy made a motion to adjourn. Secretary Ureña seconded the motion and all agreed.