

Brain Injury Commission

Meeting Minutes

June 3, 2019

10:00 a.m. – 12:00 p.m.

Date of meeting: June 3, 2019

Start time: 9:59 a.m.

End time: 11:58 a.m.

Location: Massachusetts State House, Room 428, Boston, MA 02108

Members present (sorted by last name):

Beth Adams – *Massachusetts General Hospital*

Dr. Imiogele Aisiku – *Brigham and Women's Hospital*

Dorothee Alsentzer - *for Dan Tsai, Assistant Secretary, MassHealth*

Rep. Gerard Cassidy – *Massachusetts House of Representatives*

Senator Harriette Chandler – *Massachusetts State Senate*

Rep. Kimberly Ferguson – *Massachusetts House of Representatives*

Nicole Godaire – *Executive Director, BIA-MA*

Dr. Swathi Kiran – *Boston University*

Adelaide Osborne – *MA Rehabilitation Commission*

Toni Wolf – *Commissioner, MA Rehabilitation Commission*

Yves Singletary – *Department of Public Health*

Dr. David K. Urion - *Boston Children's Hospital*

Marilyn Price Spivack – *Family Member, Founder of BIAA& BIA-MA, Spaulding Rehabilitation Hospital*

Members participating the meeting through conference call line:

Helene Robillard – *Brain Injury Survivor*

Members absent:

Beth Hume (Representing Dr. Monica Bharel)

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*

Secretary Francisco Uréna – *Department of Veteran Services*

Proceedings

Senator Chandler called the meeting to order at 10:03 a.m. Members introduced themselves around the room.

Senator Chandler and Representative Ferguson asked Ms. Nicole Godaire to announce a moment of silence for Arlene Korab.

Representative Ferguson asked for a motion to approve the minutes from the Commission's last meeting on May 6th; Nicole Godaire requested that "family member" be added to Marilyn Price Spivack's title. The Commission casted a voice vote and unanimously approved the meeting minutes.

Dr. Imiogele Aisiku started his presentation at 10:12 a.m. He presented the most recent data of Brigham and Women's Hospital trauma demographics from April 2016 to January 2019. Dr. Aisiku pointed out that 54.6% of the Traumatic Brain Injury (TBI) patients from his hospital were on MassCare; and 31.4% of all patients discharged from his hospital chose to use home care for which there was no cognitive data. 43 numbers of referrals produced, and 10 scheduling success, 12 number of clinic visits. Dr. Aisiku acknowledged the challenges for referred patients to receive medical help at his hospital, including insurance problems and language barriers. Dr. Aisiku pointed out that of the TBI patients his

hospital received, male/female ratio was almost even which was within his expectation. Dr. Aisiku finished his presentation at 10:21 a.m. and opened for questions.

Ms. Dorothée Alsentzer asked Dr. Aisiku about the hospital's category standards for stroke patients, and Ms. Marilyn Price Spivack stressed the need for a name-attached TBI registry system; she also pointed out that the data was lacking for substance abuse and the close connection between TBI and substance abuse. Dr. Swathi Kiran asked Dr. Aisiku to clarify the discharging process for TBI patients who decides to use home service and the reason why there is no cognitive data for the group. Dr. Aisiku answered that the assessment and evaluation process to acquire cognitive data for TBI patients follows a set of professional standards that needs manpower and equipment, which was hard to ensure for patients under home service; in addition, home service patients tend not to follow up with the hospital.

Ms. Beth Adams started her presentation on the continuum of brain injury rehabilitation and care at 10:28 a.m. She stressed that there are currently loopholes in the services of BIA rehabilitation services, which inhibit patients from being able to receive comprehensive and continued service. She listed some common questions that patients normally ask, and highlighted that it is critical to create consistency in brain injury rehabilitation service. She pointed out some gaps in the continuum of care

- Those working with a patient with a brain injury may not be aware of appropriate resources;
- Funding may no longer exist for that service;
- Providers may no longer be in business;
- Despite providers referring individuals to resources the ball may be dropped without following through;
- Family too overwhelmed to call when they arrive at next destination; or may forget and not follow up
- Waiting lists are too long to wait for services.

She pointed out the importance of advocating and she listed some ways to advocate effectively on behalf of brain injury patients. She then listed the state resources that are available and that patients need to be aware of. She also listed some private resources that are available. She suggested the Commission work on how to bridge the gap between services, so as not to let people fall between the cracks, and to have thoughtful conversations to discuss the impact that funding may have. She described her goals as Bridging the Gap: transitioning from inpatient to outpatient care. She finished her presentation at 10:39 a.m.

Ms. Marilyn Spivack pointed out that as the healthcare industry is changing rapidly, there are many new challenges and Massachusetts needs to update its system to provide the right process of care to avoid reoccurring problems and she emphasized the importance of having a brain injury registry system which can effectively help track TBI patients.

Rep. Ferguson asked every member about what should be included in the final report to help ensure the state has adequate skilled nursing facilities.

Dr. Aisiku expressed that providers tend to have a hard time directing TBI patients to the next suitable service and he also pointed out that TBI patients who have multiple injuries may neglect next level TBI care, while focusing on their other injuries.

Rep. Cassidy acknowledged that the next presentation would be from Dr. Chris Carter from Spaulding Rehabilitation Hospital on IRF level of care for brain injury at 10:43 a.m. Dr. Carter introduced the services and covered areas that Spaulding provides. He then explained the criteria for a referral to an intense rehabilitation facility (IRF): (1), the facility to have sufficient medical stability to be able to participate in a minimum of 3 hours daily therapy, (2) have medical complexity/acuity requiring daily monitoring by MD, and (3) have the potential to achieve realistic functional goals allowing patients to return to their community. Dr. Carter highlighted the unique resources that Spaulding provides and noted that those patients who can tolerate long recovery sessions of more than 3 hours are eager to come to Spaulding's facilities for treatment. Dr. Carter introduced that the Spaulding has four inpatient facilities and further explained the services and covered area of them. He then explained the functions of their interdisciplinary team in detail. Dr. Carter presented data of Spaulding's Adult Brain injury program of 2018, during which 410 patients were served. Dr. Carter explained some data including: the data of Spaulding's discharge destination for TBI patients, the data for Spaulding's Stroke program of 2018 (of which 605 patients were served). Dr. Carter explained the funding

Spaulding received for these two programs as: private (BC/BS, Aetna, HCHP, WC, etc.) and Medicaid and Medicare. Dr. Carter listed the primary causes of Spaulding's brain injured patients, which include head trauma, vascular disorders, degenerative disorders, toxic exposure, infectious processes, etc. Dr. Carter explained the eight severity levels of brain injury according to Rancho Los Amigos Scale, and he identified the levels that need IRF. He explained the physical and psychological issues brain injury patients can face and how they can be helped. Dr. Carter underscored the family impact brain injuries can cause and the importance of helping the family to adjust and live with brain injured members. Dr. Carter also emphasized the needs of caregivers, acknowledging that the caregivers need help as much as the brain injured patients in the ways as case management with service coordination, resource planning, legal and financial counseling, informational, emotional and instrumental support as well as trainings. Dr. Carter finished his presentation at 11:23 a.m. and started taking questions from Commission members.

Ms. Adelaide Osborne asked for Dr. Carter's insights on areas that need to be improved to ensure the consistency of brain injury services. Ms. Marilyn Price Spivack highlighted the importance of some information's presented by Dr. Carter. Rep. Cassidy appreciated Dr. Carter's presentation.

Ms. Eileen Chernoff and Ms. Ann Gillespie from Community Rehab Care started their presentation at 11:35 a.m. They introduced that the Community Rehab Care is licensed as an Outpatient Rehabilitation Clinic, and it offers Physical, Occupational and Speech Therapy and Wellness Programs for Neurological and Orthopedic clients in a community reintegration model. They are the only independent clinic of its kind in Massachusetts. Ms. Gillespie explained the procedure and concept of post-acute journey, and used a patient's example to show the post-acute needs of brain injured patients.

Representative Ferguson noted that the venue for the ongoing Brain Injury Commission meeting was only reserved to 12 p.m. Acknowledging the importance of Community Rehab Care's presentation, Rep. Ferguson asked whether they were willing to hold off on the rest of the presentation and to go into details in the next meeting, which was pleasantly agreed by Ms. Chernoff and Ms. Gillespie. Time was 11:46 p.m.

Ms. Michelle Martin and Mr. Tony Simonelli from Brockton Area Multi-Services, Inc. (BAMSI) started their presentation at 11:46 p.m. on their community based services, day programming, and residential supports. They showed the Commission a four minute video featuring the patients that they helped to integrate back to the community. Ms. Martin introduced the service and model BAMSI provides. The presentation was completed at 11:57 p.m.

Senator Chandler noted that the next meeting will be held on July 9th, and asked members whether there are remaining questions; seeing none, Senator Chandler asked the Commission to adjourn the meeting. A motion to adjourn the meeting was filed, seconded and voted on unanimously by the Commission. The meeting was adjourned at 11:58 a.m.