

Brain Injury Commission

Meeting Minutes

April 1, 2019

1:30 p.m. – 3:30 p.m.

Date of meeting: April 1, 2019

Start time: 1:30 p.m.

End time: 3:31

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

Members present:

Beth Adams
Dorothee Alsentzer
Rep. Gerard Cassidy
Senator Harriette Chandler
Rep. Kimberly Ferguson
Nicole Godaire
Beth Hume (Representing Dr. Monica Bharel)
Dr. Swathi Kiran
Carole Malone
Adelaide Osborne
Undersecretary Lauren Peters
Senator Dean A. Tran
Secretary Urena
Toni Wolf
Helene Robillard

Members absent:

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Proceedings

At 1:32 Senator Chandler called the meeting to order.

Representative Kim Ferguson, Representative Gerard Cassidy, and Senator Dean Tran introduced themselves and discussed the importance of the Commission.

The members of the Commission introduced themselves and their affiliation with the Commission.

David Giannotti, Public Education and Communications Division Chief of the State Ethics Commission, provided the Commission with a brief overview of the State's conflict of interest and ethics regulations. He explained Commission members' status as special state employees, and explained the considerations related to conflicts of interest and mandatory online ethics training they are required to complete within 30 days of their appointment.

The Commission took a group photo.

Lauren Cleary, Associate General Counsel for the Executive Office of Health and Human Services, provided an overview of the Open Meeting Law. She emphasized the importance of transparency and reminded commission members that, records, documents, and minutes from the commission's meetings are public records. She acknowledged that there are 19 members of the Commission and that the number to constitute a quorum would be 10. She informed the members that a form is needed to be signed by every member to indicate that the briefing was presented. She introduced relevant regulations to maintain the transparency of the meeting. Cleary explained the importance of email communication and its danger with violating Commission rules. She explained rules regarding creating subcommittees. Cleary explained rules regarding remote participation, which is a decision that needed to be voted on and approved by

the Commission as a whole. Cleary highlighted that emails and other communication between the members are public records and are subsequently subject to corresponding laws.

Rep. Ferguson highlighted the importance of rules regarding quorums over email.

Dr. Swathi Kiran asked for clarification of the definition of public records, which was answered by Cleary.

Robert Jones, Deputy Chief of Staff of the Executive Office of Health and Human Services, introduced himself and asked all the support staff in the audience to introduce themselves. Mr. Jones guided the Commission members to complete the form stating they received the full briefing on Open Meeting law.

Secretary Francisco Ureña arrived.

At 2:15 pm all members were sworn in by Robert Jones.

Open Meeting Law's forms signed by the members were collected.

Senator Chandler presented the Brain Injury Commission charge. The Commission is set up by section 2A of chapter 4 of the General Laws to review data concerning brain injury and the needs of individuals with acquired and or traumatic brain injury. She explained that traumatic brain injury is now included in the definition of acquired brain injury; the Commission shall review the recommendations of the Special Commission established in section 160 of chapter 131 of the acts of 2010 and provide updates, and that the Commission shall review relevant services and the Commission shall file a report of its finds and recommendations with drafts of legislation necessary for executing those recommendations.

Rep. Ferguson explained that the current deadline of June 30, 2019 for the Commission to file the report is subject to change, and will be discussed at a future meeting.

Senator Chandler brought up the possibility of remote participation.

Vote: At 2:19 Secretary Ureña introduced a motion to allow for remote participation, which was seconded by Beth Adams, and was voted on unanimously by the commission via voice vote.

Nicole Godaire of the Brain Injury Association of Massachusetts (BIA-MA) introduced the history of the Commission as it was first created in 2011 in response to a report that noted the need of attention to brain injury on a state level. Ms. Godaire walked the members through the past work of the Commission (see slides), which includes: HITS trust fund (Head Injury Treatment Service trust fund), Administrative recommendations, and services recommendations (including five regional day program, five regional ABI Multiservice center, and relevant study reports). Ms. Godaire elaborated more on the accomplishments of 2011 Commission, which includes the first comprehensive epidemiological study on ABI in the state in over thirty years. Ms. Godaire also listed the study group and gave a brief review of the epidemiological report. She then summarized accomplishments regarding needs assessment, and briefly introduced the pilot community center in the state's fiscal year budget from BIA-MA and the Cognitive Rehabilitation Bill.

Senator Chandler raised a question regarding the current insurance coverage rate. Godaire explained that the current coverage is at a satisfying level and continued to explain the cognitive rehabilitation bill.

Senator Chandler supplemented Rep. Ferguson with her vision for the program and mentioned that the date for the reporting deadline needs to be changed. She reassured the Commission that a request was put into next year's FY budget to support the Commission's mission, and that there would be adequate time for the Commission to change the reporting deadline. Senator Chandler highlighted the importance of visiting brain injury rehabilitation centers to understand the toll and hardship of families experiencing brain injury.

Senator Chandler asked every board member what their visions are for the Commission.

Dr. Kiran answered the question that her intention is to help the Commission and to expand the program for younger adults. She acknowledged the gap in locational services between people who are in vocational training and people who just completed the training.

Beth Adams acknowledged the gap between different levels of care and that, as providers change, people can't find the service they need. She hoped that there could be a comprehensive care system that would accompany survivors all the way. Ms. Adams also applauded the fact that TBI and ABI are now in the same category, and expressed her wish to increase awareness of this integration so that we can start to share treatments and resources between these two categories.

Nicole Godaire explained the reason for that TBI and ABI were initially separated as two different groups.

Adelaide Osborne mentioned that legal language should be updated regarding the integration of the two categories.

Dorothee Alsentzer stated that one of her visions for the Commission is to find a way to leverage MassHealth experience, so that people with brain injuries across the state who are not eligible for MassHealth can get the same help and treatment.

Undersecretary Lauren Peters stated that her vision for the Commission is to ask for additional funding² for treatments of brain injury survivors, to make people more aware of shorter term solutions, and to create streamlined services and programs with different agencies to better support survivors as the patients transfer from short term care to long term care.

Senator Tran mentioned that concussions are one of the leading causes of brain injury and that concussions are very likely to occur while people engage in sports activities. Senator Tran stated his wish for the Commission is to raise people's awareness of this cause and to take appropriate actions in preventing concussion-related brain injuries.

Rep. Cassidy briefly stated that he was looking forward to continued service with the Commission.

Rep. Ferguson briefly mentioned that she intends to continue the great work of the Commission

Toni Wolf stated that she believed there's little understanding among the general public about the distinction between brain injury and other types of injury, and hopes this commission can promote awareness of acquired brain injury in general. She also would like to enhance long term support systems so that patients would not be "penalized" as their health improves as a result of getting treatment.

Beth Hume expressed appreciation for the accomplishments of the past Brain Injury Commission. She also expressed concerns that the Commission might accidentally focus on TBI while neglecting other brain injuries.

Secretary Urena stated that he would like to see the practitioners care for veterans-related brain injuries; he acknowledged the current gap in the supplement, and looked forward to creating opportunities to collaborate on improving treatment courses to meet veterans' needs.

Carole Malone noted that older adults are experiencing a rising number of brain injuries, and that stroke can also lead to brain injury. She mentioned that the Commission needs to confirm that resources are provided to the survivors.

Nicole Godaire reflected on the Brain Injury Association's history and highlighted the shortage in care for patients of acquired brain injury (community based, long-term, and transitional), calling it a bigger piece of the picture to ensure that acquired brain injury survivors understand their situation and seek medical attention and rehabilitation in a timely manner.

Helene Robillard spoke from her own experience, stating that patients are often not fully informed of their brain injury conditions and survivors might underestimate their own conditions and perform extraneous tasks that can be harmful

for their situation. Robillard described that a patient's brain injury might be overlooked in some traumatic accidents, such as car accidents, due to the fact that people only focused on other visible traumas while neglecting brain injury, which can ultimately result in patients not acknowledging their injury at all or underestimating their brain injury and perform normal tasks that can be harmful, like watching TV.

Adelaide Osborne acknowledged that experts are equipped with the knowhow to deal with brain injury, and highlighted that holding public forums are the best way to inform the broader audience. Osborne also pointed out that the report of this Commission in 2011 needs to focus more on children under 18 and elders above 60.

Beth Adams supplemented the necessity of ensuring elders' situations are fully attended to and considered.

Senator Chandler pointed out the fact that ABI still remains a problem to be recognized in the rest of the country. She then acknowledged the progress in the field within Massachusetts. She suggested that members study the materials provided to them in order to acknowledge the accomplishments of the Commission in the past and the work that must be pursued in the future. She invited members to contribute to the procedures and tasks of the commission freely. She shared her experience in dealing with the subject and noted that it is very important to get involved personally, to put a "personal face" to the subjects that the Commission works with. Senator Chandler shared a story about one of her constituents who inspired her to get involved with Brain Injury in Massachusetts.

Adelaide Osborne asked about the possibility of updating the data collected by the commission.

Senator Chandler expressed her concern about the cost of the data and its necessity.

Beth Hume explained that her organization has partial updated data on hand.

At 3:18 p.m. Senator Chandler acknowledged Hume's remarks and asked the commission about spending resources to update the data.

Undersecretary Lauren Peters expressed her opinion that data should be viewed separately and that the Commission should reserve the resources to update only the most relevant and needed data.

Undersecretary Peters asked Secretary Urena about the reasons why there was a lack of data on veterans.

Helene Robillard Brought up that it is difficult to collect data on some folks with ABI because they do not always know they have one. Senator Chandler asked about information related to sports concussions; Beth Hume confirmed that the Department Of Public Health has some data on sports concussions.

At 3:23 p.m. Senator Chandler proposed that the Department of Public Health should help the Commission with relevant data. Senator Chandler summarized the discussion and asked members to consider what data they believe is missing, as well as what data they have the access to in their own capacity, and asked members to share those findings at the next meeting.

Representative Ferguson reminded members to sign the provided forms.

Senator Chandler informed the Commission that the next meeting will be May 6, at 10:00-12:00 in the State House Room 428.

Nicole Godaire introduced a motion for the meeting to adjourn, which was seconded and unanimously approved. The meeting adjourned at 3:30.