

Brain Injury Commission

Meeting Minutes

October 1, 2019

12:00-2:00 pm

State House, Room 428

Date of meeting: October 1, 2019

Start time: 12:10 pm

End time: 2:00 pm

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

Members present (sorted by last name):

Beth Adams – *Massachusetts General Hospital*

Dorothée 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*

Carole Malone – *Assistant Secretary, Office of Elder Affairs*

Yves Singletary – *for Dr. Monica Bharel, Department of Public Health*

Secretary Francisco Ureña – *Department of Veteran Services*

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

Senator Dean A. Tran – *Massachusetts State Senate*

Toni Wolf—*Commissioner, Massachusetts Rehabilitation Commission*

Members participating the meeting through conference call line:

Helene Robillard – *Brain Injury Survivor*

Members absent:

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

Adelaide Osborne – *MA Rehabilitation Commission*

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

Undersecretary Lauren Peters – *Executive Office of Health and Human Services*

Proceedings

Representative Gerry Cassidy opened the meeting at 12:10. Dorothée Alsentzer motioned to approve the September 10th minutes; Secretary Francisco Ureña seconded the motion.

Beth Adams began her presentation on Continuum of Brain Injury Rehabilitation and Care. She discussed the importance of understanding how significant hits in sports are affecting kids and what we need to do to protect them. Regardless of whether it is a contact sport or not, a concussion is still a brain injury. An important aspect of brain injury care for children in sports who have suffered a concussion is to avoid a second impact, or second concussion. Adams pointed out that some second impacts do not need to be a hit to the head to be fatal, and it's important to not make athletes get back to playing if they are not ready. An issue Adams sees with the way we treat concussions on the field are sending them to doctors not well versed in neurology who may clear them too soon, making them more susceptible to a second impact.

Peer pressure is a significant aspect of sports concussions. Students want to get back to games quickly as to not let down teammates or miss any of the action of the game. The blame for missing these games should not be placed on the victim of a concussion, but rather the medical team who, correctly, asserts they should not be playing. This saves impressionable teens and kids from feeling pressured or self-conscious about not being able to play.

As far as solutions to these issues, there are perimeters in place but no where near where they should be. Adams cited Commissioner and former NFL player Ted Johnson's experiences with concussions throughout his football career, including how coaches saw his concussions as an invisible disease and put him back in the game. There is too much of a "suck it up" attitude in competitive sports. Dr. Swathi Kiran asked about impact tests and whether they're standardized. There was discussion around how athletes need to be taken off the field entirely to be tested and given a neuro score which should decide if they can come back in the game. Great allies in these situations are athletic trainers who can be an eye and ear for coaches and doctors.

Signs and symptoms of an impact include: irritability, moodiness, foginess, isolation from friends and family, laughing/crying easily, sensitivity to light

Gaps in continuum of care include: incorrect providers making incorrect neurological diagnoses, students may need a 504 plan but it goes undetected, and poor follow through from referring providers making care fall through the cracks.

Concussion protocol: at the NFL level, there are physicians on standby to double check the eyes and ears to look for initial symptoms. The commission discussed the importance of having a standardized protocol, and having physicians at the school level as well. The "Monday morning" provider needs to be supported to have the proper resources to refer the student/athlete down the correct path for care.

Important local and state resources: PCP, BIA-MA, SHIP. Ms. Adams later noted that MRC and SHIP are great resources that often times people do not know how to get in touch with. There should be a more streamlined way to communicating with them from the hospital setting.

Ms. Adams went on to explain that all concussions are different, they all need time to heal, and they all require different care. Going to the improper care provider can lead to fatal results (go to a cardiologist for a heart problem, neurologist for a head injury).

Nicole Godaire confirmed that only schools compliant with The Massachusetts Interscholastic Athletic Association regulations have a plan in place for concussions, including keeping record of students who suffer injuries. Ms. Godaire referenced the Boston Medical Center report that covered this information.

Marilyn Spivack brought up that education on head injuries is greatly lacking. There can be a group of nurses and pediatricians who understand concussions, but Ms. Spivack said that it should be mandatory that school nurses and programs are equipped with concussion education, especially given that treatment plans have changed so much in recent years and continue to change. School nurses are a significant provider. Considering how much time kids spend in schools, nurses should be set up for successful outcomes. Depression and anxiety is huge after injury and the state needs to incorporate that into the education to see the whole student and understand that's a very real diagnosis.

Dr. Swathi Kiran asked if the criterion for kids returning to school after diagnosis is the same around the state, which Ms. Adams clarified that there is no criterion for kids coming back to school right now. A conversation regarding district wide criterion ensued, with Representative Kim Ferguson proposing that each district having a "concussion coordinator", someone who can monitor students who have suffered a head injury and make sure they are being cared for. School nurses play this part most of the time, but there is only one per school in many instances and they are overwhelmed. There are also inconsistencies with reporting, especially when kids transfer from private to public schools. Senator Chandler brought up

that while reporting is important, it's what we do with the information that can be vital. Ms. Godaire clarified that schools under MIAA have mandated reporting, and there are DPH guidelines in place, but they are from 2011. Most nurses are reporting injuries, but there is no formal law outlining what to do. Ms. Alsentzer believes it would be difficult to legislate all mandated reporting on account of there are too many concussion events (at home, outside of school, on the weekends) that "reporters" would not be aware of. Ms. Godaire clarified that the regulations for DPH for Return to Learn are only for public middle and high schools, only grades 6-12, and only private schools under MIAA. All schools that fall under MIAA must have a head injury plan in place.

Representative Ferguson asked if the commission has an idea on how many sports related concussions are reported to DPH, which Yves Singletary of the Department of Public Health said he could look into and report back to the commission.

Representative Ferguson asked how the research on CTE has come in to play, but Ms. Adams says that the research is so new that we still cannot pinpoint if they have the disease until their brain can be looked at after they pass away. Doctors can see signs and symptoms and tell survivors to hone in on those things but there is no medical answer to Representative Ferguson's question. Dr. Kiran highlighted the work being done at Boston University.

Senator Chandler went back to the question of reporting and wondered if the state would actually be able to report on "weekend concussions". Ms. Spivack honed in on the importance of educators and school nurses being equipped to see and be aware of changes to students on Monday, i.e. behavior changes, irritability, and learning capacities. She noted that it is unwise to assume all parents are on top of this, and that it can be very easy to ignore if you or your child has a concussion. Again, she highlighted that this is an education and awareness issue, and seconded the idea that there should be a central person in each district able to handle these injuries.

Ms. Godaire brought up that a significant amount of consumers testified at the Brockton listening session that if they did not have a sports related injury, they were not treated or referred to the right doctor. Doctors are marketing themselves as sports injury providers and alienating a large group of consumers who do not have a sports concussion or injury.

Ms. Spivack also noted that child abuse is a contributing factor to concussions, but is not always something we discuss. Ms. Adams agreed, and again highlighted that school nurses play a key role with these kids as well.

Senator Chandler asked about the possibility of having the Governor declare a Brain Injury Awareness Day to have key stakeholders from New England come together to raise awareness.

The next meeting will be November 12th.

The commission discussed future programming of meetings including, hearing from Homebase, insurance providers, DPH, and MRC

Ms. Spivack flagged for the group that it was the first day of a new regulation for patients with head injuries who require skilled nursing facilities. Ms. Alsentzer and Secretary Carole Malone said they will look into this, and see if any aspect should be included in the commission report.

Representative Ferguson expressed the need to visit Cape Cod to hear from consumers on the Cape and Islands to finish off the regional listening sessions. She also encouraged commissioners to familiarize

themselves with the 2011 BIC report to come up with ideas and have the background necessary to discuss the future report.

Senator Chandler pointed out the need to be prepared to have a budget ask for FY'20 to have more clubhouses in Massachusetts similar to the space opened in Worcester following the first iteration of the Brain Injury Commission. Ms. Godaire offered the assistance of the Brain Injury Association in the process of writing the report.

In preparation for the next meeting, Ms. Alsentzer and Secretary Malone emphasized the importance to have a guideline that each presenter can abide by to avoid gaps in information. Secretary Malone added that the commission needs to understand what resources are available and what basic insurance is offering consumers.

The next meeting of the Brain Injury Commission is November 12 at 12:00 pm at the McCormick Building, 1 Ashburton Place, 21st Floor Room 2. The visit to Cape Cod will be December 3rd and there will be another Brain Injury Commission Meeting on December 9th at 10:30 am, State House room 428.

Ms. Alsentzer motioned to adjourn, seconded by Secretary Malone.