

Brain Injury Commission

Meeting Minutes

December 9, 2019

10:41am-1:12 pm

State House, Room 428

Date of meeting: December 9, 2019

Start time: 10:41am

End time: 1:12 pm

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

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*

Ted Johnson – *Former NFL Player, NBC Sports Analyst*

Dr. Swathi Kiran – *Boston University*

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

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

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

Senator Dean A. Tran – *Massachusetts State Senate*

Secretary Francisco Ureña – *Department of Veteran Services*

Toni Wolf—*Commissioner, Massachusetts Rehabilitation Commission*

Members participating in the meeting through conference call line:

Helene Robillard – *Brain Injury Survivor*

Members absent:

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

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

Adelaide Osborne – *MA Rehabilitation Commission*

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

Proceedings

The meeting was called to order at 10:41 by Representative Ferguson. Representative Cassidy made a motion to approve the minutes. Mr. Singletary proposed edits, specifically to clarify thoughts surrounding a future epidemiology report. Ms. Alsentzer made the motion to accept as amended, Secretary Urena seconded the motion. All approved.

Representative Ferguson thanked HomeBase, a veteran care program through Massachusetts General Hospital, for attending and both Ms. Adams and Secretary Urena for coordinating. She asked if either would like to comment before HomeBase began. Ms. Adams introduced Dr. Zafronte from HomeBase and noted that Dr. Iaccarino would be joining shortly. Dr. Zafronte

began his presentation on *Programs for traumatic brain Injury and Cognitive Health*. His slide deck may be accessed on the Brain Injury Commission's website. Dr. Zafronte noted that veterans with brain injuries are more apt to become homeless. He touched on the overlap between PTSD and persistent post-concussive symptoms. He noted that social isolation is a huge factor for employment, cost and functionality of veterans with brain injuries. He explained there is no single test to diagnose a concussion. There is a network of complex symptoms, including physical, emotional, and cognitive. He stressed the importance of the sense of hope and connectivity for people. Thus, they have divided the program into multiple domains which includes: regional outpatient clinic, a two-week intensive clinical program, a 2 day ICP TBI assessment program, and a 4 day multidisciplinary intensive clinical program for special operator forces.

Representative Ferguson commented that all the pieces are super important but from her experience it is often the executive function piece that breaks down in the day to day living. Dr. Zafronte agreed absolutely, and stated there are a lot of people who don't have attention. He turned to Dr. Iaccarino and she commented that there are a lot of people who can't focus and can't attend to things because they can't remember. There may be a variety of issues, along with TBI that don't allow them to pay attention.

Dr. Zafronte commented that he thinks attention is the base. He stated that someone may have sleep dysfunction and other paradigms that contribute to the lack of function, and in fact, 92% have sleep problems.

Dr. Zafronte passed the presentation to Dr. Iaccarino, who continued. She stated that HomeBase begins with a two day comprehensive evaluation. A majority of military members have had at least one concussion, so every veteran receives a cognitive assessment screen. They particularly use language that service members would find most relative to their own life.

Senator Chandler asked if all the patients are volunteers. Dr. Iaccarino confirmed.

Dr. Iaccarino continued with her presentation, noting that in their studies both post concussive symptoms and depression go down, while satisfaction in their participation in the world had gone up.

Commissioner Wolf asked how long the data period was. Dr. Iaccarino responded that pre-testing data was when the patient came in and post data was after 2 weeks. She stated that the researchers are trying to continue collecting data, but it is very hard to collect longitudinal data. These researchers are eager to know if the treatment lasts.

Dr. Zafronte added that the data is quite compelling because the impact is so large. Dr. Zafronte continued the presentation. He noted that pain and cognition are linked. He stated that pain, in and of itself, is a brain inflammatory. He continued by stating that the idea of exercise safety post-concussion has evolved over time. It was a common medical suggestion to say no activity and complete rest after a concussion. However, now a series of studies support that a brief period of rest followed by exercise is more appropriate. Dr. Zafronte stated that the more one is kept in isolation the more you make them feel badly, which produces changes in the brain.

Senator Chandler asked how much of the research and data is shared with private and public resources, noting that his research is incredible and has incredible implications. Dr. Zafronte answered that he is pleased to share all of the data and that they try very hard to quantify what they do. He stated that what is good enough for today, is not good enough for tomorrow.

Commissioner Wolf asked how to better coordinate to provide support. Dr. Zafronte answered that they are very open to collaboration.

Senator Chandler asked if they are currently coordinating with anyone, for example the Massachusetts Rehabilitation Commission. Dr. Zafronte stated that while he is not in charge of collaborations, they have published the data and are very open to sharing and collaborating.

Senator Chandler asked what avenues currently exist that can make use of the data. Dr. Zafronte pointed to their tie with Massachusetts General Hospital, which is very mission oriented. Ms. Godaire noted that the staff at the Brain Injury Association of Massachusetts also connects with HomeBase staff.

Dr. Zafronte noted that they also do a lot of outreach to veterans, including events, to make sure they are aware of these services.

Representative Ferguson noted that the Commission has heard from a lot of survivors at the listening sessions that they feel isolated, especially when they don't qualify for services. She stated if they had a group to go to, even a couple times a week, it would help spread the message of hope. She believes that this HomeBase program can be a model for other survivors.

Dr. Zafronte answered that they are more than willing to share anyway that they can. He stated that the program started with a very small cohort at first and to try to do it for the community as a whole would have been very difficult.

Senator Chandler reiterated that she had always heard that rest after a concussion is the best care, and confirmed that research is now saying that exercise is the best. She asked if that is something of which the public should be made well aware.

Dr. Zafronte answered that the evidence is piled up. He stated that while they are happy to share knowledge and data, one problem is making this data applicable to the real world. He informed the Commission that they have an internet based teaching program. They have also gone to VA's over the country and have reached a large number of consumers. Through the HomeBase training institute they've educated 70,000 providers in various aspects of care. He stated that they aren't looking to disengage the community, they are looking to reintegrate them.

Ms. Adams stated the Commission has been discussing the continuum of care. As hard as providers try, people fall through the cracks, but this conversation fosters a good discussion on how to ensure that doesn't happen.

Ms. Spivack questioned how to mix the civilian population with veterans. The issue, particularly in rural areas, is the isolation and lack of socialization. She wondered if there is a relation between a service person with a head injury and a civilian with a head injury will they come together; will their socialization become more enhanced? She believes it would. She further stated that when veterans go back to their rural residences, they may not have other veterans with head injuries, but they will likely have civilians.

Ms. Godaire noted that often times state agencies get startup funding to look at small portions of the population, but don't get continued funding.

Senator Chandler asked where to go from this point. There was minimal participation from veterans and none from athletes in prior Commissions, but now the Secretary of Veteran's Affairs and Ted Johnson are on the Commission. She asked how to institutionalize this relationship, because it is very critical to create these ties.

Mr. Johnson stated he felt it is a natural grouping between athletes and veterans. Senator Chandler answered that it doesn't currently happen. Mr. Johnson responded that it will have to be figured out. From his personal experience at Spaulding Rehab he spent a lot of time with veterans and they naturally hit it off.

Dr. Iaccarino mentioned a study where a veteran was partnered with a former NFL player and it went very well. There are a couple programs where they bring elite athletes and elite military members together. These studies were very preliminary and one barrier is insurance coverage. Group therapy, cognitive health group, fitness group, art group, all these groups that combat isolation are not reimbursable. She stated it would be challenging to be sustainable outside of the HomeBase program.

Dr. Zafronte stated that there are a lot of complimentary weekend and group activities that really build bonds, which includes a lot of intense case management, which would not normally be covered. He believes there here is a natural symbiosis between athletes and the military.

Senator Chandler responded that the ClubHouse approach has been discussed many times. There is proof that it produces results, but there is a financial issue. She asked if both the military and civilian population feed into the ClubHouse is there is a possibility of getting any financial help from the military.

Secretary Ureña answered that logistically coordinating the travel veterans and the travel itself is a huge financial undertaking. He believes that are some gaps that go above and beyond the HomeBase program, when translating this approach to the civilian population.

Commissioner Wolf asked what linkages should be looked at to apply this approach to the long term, as it is equally as critical as treatment.

Dr. Zafronte stated there are things that need to be accounted for, such as homelessness. There are probably five or six structural areas that need to be thought about, so that people can be helped within the realms of reality.

Ms. Spivack mentioned that often individuals are helped by helping others. She proposed that while the veterans are participating in the two week program with HomeBase that the Brain Injury Association makes a connection with them, so that when they go back to their rural communities they can connect to a brain injury support group. That perhaps, because they got this push forward, they can help someone else and give someone else hope. She believes if we begin to connect individuals we may take a step forward.

Dr. Zafronte answered that he thinks she is right, but case management is crucial to doing more. He stated that the Secretary is correct, that it took a decade of hard work to build what is now a national resource.

Representative Ferguson stated that as much progress has been made, case management is still missing, which is a huge piece of the problem.

Senator Chandler asked if HomeBase would be willing to help the Commission. For example, if the Commission recommends developing a pilot program using the HomeBase model of two weeks and determines a way to get athletes and veterans working together to produce lasting results. She stated that she believes Ms. Spivack's idea is excellent.

Ms. Godaire asked Dr. Zafronte if he would be willing to share the operating budget of HomeBase.

Dr. Zafronte answered that he did not feel comfortable sharing that information without prior permission.

Secretary Urena stated that he thinks it is important to know because the Commission is focused on finding best practices and funding. He noted that a lot of HomeBase is done through fundraising and that they have budgetary allowances that the State does not.

Ms. Godaire asked if Dr. Zafronte would be willing to share best practices.

Dr. Zafronte answered that he would be thrilled to share best concepts. He stated it is key to identify the most valuable elements that can be taken out to the community.

Ms. Spivack asked if there is allowance in the HomeBase budget to add a position specifically tasked with following participants and their progress through the years. She feels it would be helpful to know for civilian purposes.

Dr. Iaccarino answered that they are working on data from one year out, however it is very challenging to keep the cohort together.

Ms. Spivack asked if the patients are aware of the importance of providing information and wondered if they could be asked to make a commitment, at the beginning of the program, to provide updated information.

Dr. Zafronte answered that would require significant resources.

Representative Ferguson thanked Dr. Zafronte for coming and sharing the information he presented.

Dr. Zafronte thanked the Commission for their passion on the subject, and reiterated that he would be happy to help the Commonwealth in any way possible.

Representative Ferguson called for a brief recess.

After a brief recess Representative Ferguson thanked Commissioner Wolf for providing information.

Commissioner Wolf began her presentation by noting that Mass Rehab Commission is not just vocational rehab, as Dr. Zafronte had said. Commissioner Wolf noted that Deloitte would present, but stated that a massive problem is that she cannot pull data by demographic. It makes it impossible to analyze money spent on specific programs, such as day services. There is a lot of money spent on different services, but without the data, she is unable to identify what is good practice. A key requirement is to figure out how to really analyze the data.

Senator Chandler asked if she is hoping to do a strategic plan.

Commissioner Wolf noted that the audit is a big piece for MRC to have a solution, so the data can be reviewed. She stated the Commission was impressed by Dr. Zafronte's presentation because he had data. While the MRC has a lot of information, they are unable to access the data.

Senator Chandler asked if there is a funding issue.

Commissioner Wolf answered, always.

Dr. Kiran asked if it is solely a funding issue.

Lindsay Huff from Deloitte begins her presentation.

Senator Chandler clarified that the system Deloitte is discussing is not yet in the works.

Commissioner Wolf stated that she is correct. The system is not yet in the works, but it is what MRC would like to have.

Representative Ferguson asked what the average consumer interaction is now versus what it would be with the new system.

Commissioner Wolf answered that she is unsure they know. She stated it is not solely about technology. If MRC has a better technology system, then they would be able to better utilize staff. Ideally they would like to be able to follow-up with a consumer who requests information.

Ms. Godaire asked if the new system will be in compliance with the current regulations. Lindsay responded yes, the new system will be able to track and flag entry points. The new system will be able to track and flag entry points.

Ms. Adams questioned the user friendly ability of the process for consumers who are unable to use a portal.

Ms. Huff asked if this was because the consumer may need assistive technology or other accommodations, which Ms. Adams confirmed. Ms. Huff answered that all state-wide internet systems are required to meet certain criteria and requirements for diverse communication needs.

Ms. Adams added that cognitive needs also need to be considered.

Commissioner Wolf admitted that the process is cumbersome and needs to be fixed. She stated she heard at the listening sessions that MRC needs to fix the front door, including IT and a better way to access staff.

Ms. Godaire asked if there are other variables for someone to utilize it. For example, can a consumer call and have someone walk them through it.

Commissioner Wolf answered that ideally intake and referral would be in one place, so that a staff member can take that call and follow-up. Currently, she believes many staff are not using their skillsets and doing transactional work instead.

Senator Chandler asked if something like this has been requested in the budget already. Commissioner Wolf referred back to the presentation. There are two types of costs with new platform implementation: one time implementation cost and annual maintenance costs. There are currently 200 people waiting after applications have been completed. It has not yet been determined if they are eligible and they have been waiting for a year. This is a technology issue.

Ms. Spivack stated that there are more than 200 people who have not even applied because of how burdensome the whole process is.

Ms. Godaire asked if there were enough neuropsychologists to process the applications.

Ms. Biber, from MRC, answered that they just got approval to hire another neuropsychologist. She stated it would be helpful to have an updated system, as currently they pull records by hand and are tracking them manually.

Ms. Godaire agreed that infrastructure is needed and asked if 200 people waiting is normal.

Commissioner Wolf stated that she doesn't have an answer. Due to the lack of available data she does not know how many people apply every year.

Dr. Kiran noted that once this infrastructure is in place, many other problems, including continuum of care and training, will have an anchor to grow off of. She believes the lack of infrastructure leads to many loose ends.

Senator Chandler agreed and asked what other problems exist.

Commissioner Wolf answered that MRC would like to look at regulations and how internal regulations can be improved. She noted this included how to make the front door more accessible.

Senator Chandler asked Commissioner Wolf if MRC is getting enough money to be able to do basic functions expeditiously.

Commissioner Wolf stated she can't access that appropriate data to answer the question regarding funding.

Senator Chandler asked for clarification on where the funding for the waivers comes from.

Ms. Biber answered that two waivers MRC operates relate to the Hutchinson's settlement.

Commissioner Wolf stated that a waiver is just a funding mechanism.

Senator Chandler noted that there are some fundamental issues that need to be addressed. Commissioner Wolf responded that MRC can be more functional with the existing staff levels, once the system is in place. Senator Chandler answered that there are other problems, aside from the system. She expressed concern that MRC has not been able to replace 25% of the SHIP staff, which is a serious issue that must be brought to the attention of the Governor.

Ms. Adams asked how long one can expect to wait if they are, for example, getting a family member set up. Ms. Biber responded that if complete medical records are sent with the application she would estimate about 30 days. However, if MRC needs to gather the records it adds time, as that can take anywhere from 5 days to months. Ms. Adams asked if the consumer is then assigned a case manager for correspondence or if that is only the entry point. Ms. Biber responded stating that is an area they are looking to improve. MRC acknowledged that they don't do a good job supporting people through the process.

Ms. Spivack stated that at Spaulding Rehab the social workers and case managers do as much paperwork as possible for families before the patient is discharged. However, they used to have more time and now they have 28 days which is not always enough time to do the appropriate paperwork. She is concerned for families that have to deal with the paperwork.

Senator Chandler expressed concern over the timing of the commission. She stated that the funding is a critical issue that perhaps should be addressed before the Commission report is filed. She noted that she appreciated MRC's candor and wondered if the funding could be included in the Governor's budget.

Ms. Spivack stated that it is the only agency that is taking care of folks between 18-21 and 65. Ms. Godaire responded that it is the only agency that has to have a bake sale for brain injuries. Senator Chandler expressed her displeasure.

Ms. Spivack noted that there is a shortage of neuropsychologists and unless they are in the hospital setting, most do not accept MassHealth.

Senator Chandler asked Commissioner Wolf how she felt about raising concerns to Secretary Sudders before the Governor's budget.

Commissioner Wolf stated that she was fine with that and that the funding is a necessity to move forward.

Senator Chandler asked if anyone was opposed. Ms. Godaire warned that if the regulations are going to change then that needs to be discussed. Senator Chandler answered that she isn't talking about regulations at this point- just money and again stressed the need to meet with the Secretary soon.

Ms. Godaire asked if the system will include incident reporting and quality control. She stated she would advocate for one agency to have all brain injury services, but the problem is MRC can't. She asked if she would be able to go into a case file, type notes, and have MRC see them.

Ms. Huff responded that will be worked out in the design.

Commissioner Wolf asked if there will be a Cape Cod listening session. Representative Ferguson stated that staff is working on scheduling it. She stated that the next meeting would likely be the end of January.

Ms. Godaire noted that there is a new report from Brandeis, which she will share with the commission.

Senator Chandler motioned to adjourn. Representative Ferguson seconded the motion and the meeting was adjourned at 1:12.