

**Traumatic Brain Injury Services Coordinating Council
Meeting Minutes
June 26, 2019; 10:40 am – 2:40 pm
One Commerce Plaza, 99 Washington Avenue, Albany, NY
16th Floor, Conference Room 1613**

Topic	Discussion	Action/Next Steps/Who/When
Attendance	<p>Council Members Present: Nina Baumbach, Vicki Clingan (Representative of NYS Justice Center in place of Crystal Collins), Michael Davison (Vice Chair), Brent Feuz, Michael Kaplen (Chair), Donald Zalucki (Representative for OMH in place of Maxine Smalling), Cliff Hymowitz, Paul Novak, Earl Schmidt, Dr. Jeffrey Bazarian, Liz Misa (Representative of NYSDOH in place of Lana Earle), Jennifer Semonite</p> <p>Council Members Absent: Megan Clothier, Kenneth Ingenito</p> <p>DOH Staff: Maribeth Gnozzio, Teri Schmidt, Thomas Rees, Anna Ko, Stephen Casscles (Legal Affairs)</p>	
Welcome and Introductions	<p>The meeting was called to order at 10:40 am; Michael Kaplen, Chair, presided over the meeting.</p> <p>Stephen Casscles: Confirmed there was sufficient membership to meet the quorum (10 Council members present in the room).</p> <p>M. Kaplen introduced Dr. Jeffrey Bazarian as a new member of the Council. J. Bazarian introduced himself as the director of the Concussion Clinic at the University of Rochester. He explained that he has conducted considerable research in the field of traumatic brain injury.</p>	
Review and Approval of 4/5/19 TBISCC Meeting Minutes	<p>M. Kaplen introduced the minutes for the April 4, 2019 meeting for comment. S. Casscles noted that Nina Baumbach had arrived, bringing the number of voting members to 11.</p> <p>A discussion of the minutes ensued, culminating in the agreement of the membership that said minutes reflected the events of the meetings. M. Kaplen requested that minutes for future meetings be produced by NYSDOH within 30 days of the meeting and indicated that he refused to vote on the April 5, 2019 minutes because they were produced too late for any member to have an accurate recollection of the content of the meeting.</p> <p>Clifford Hymowitz made a motion to vote on the minutes for the April 4, 2019 meeting. Earl Schmidt seconded the motion. 8 members of the council voted in favor of the minutes; 3 abstained. S. Casscles indicated that the minutes were not approved. M. Kaplen reiterated his point that the minutes were too late for the members to have a valid recollection of the events of the meeting. He stated that it would be inappropriate for him to vote on them considering how late NYSDOH was in producing them. S. Casscles restated that the meeting minutes were not made official. Additionally, he asserted that the April 4, 2019 meeting minutes reflected the election of the chair and vice chair and requested that the Council reconsider voting. M. Kaplen agreed to change his vote for the April 4, 2019 minutes from “abstain” to “yea,” but reiterated that he would not vote on future minutes produced in an untimely fashion. The motion to approve the April 4, 2019 minutes was approved by a vote of 9 in favor with 2 abstentions.</p>	

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**BIANYS
Legislative and
Public Policy
Agenda, “Return-
to-Learn”**

Christina Bolton, BIANYS, presented on the organization’s legislative agenda, achievements, and their initiative, “Return-to-Play.”

BIANYS PowerPoint presentation was disseminated to the TBISCC membership and public attendees.

Following the presentation, **Eileen Reardon**, BIANYS, posited that “Return-to-Play” is thoroughly ingrained in school districts, but that “Return-to-Learn” needs reinforcement. She indicated that schools generally rely on their nurses, and that many districts do not have a nurse or share a nurse across many schools. **C. Bolton** explained that BIANYS is trying to add to their statewide roundtables and is encouraging school districts to consider sharing resources in order to implement post-brain injury protocols. **M. Kaplen** suggested that BIANYS invite a representative from the TBISCC to participate in their discussions. A discussion about payment for baseline testing for all children ensued. **C. Bolton** indicated that the Plattsburgh School District tests all children’s baseline functioning. **M. Kaplen** pointed out that these tests are not covered preventively. **Dr. Bazarian** shared that he conducts baseline testing as a follow-up because it is not covered by insurance before an injury occurs. **M. Kaplen** indicated that he believes the committee and NYSDOH should work to designate baseline testing as a preventive medical procedure so that it is covered by insurance and that re-testing after a concussion should also be covered. **Dr. Bazarian** informed the group that re-testing post-concussion is currently covered by insurance.

C. Hymowitz posited that young people often self-identify as having a TBI, but are not appropriately diagnosed or referred for services, causing difficulty for them later. He suggested that OPWDD should be included in the conversation. **Dr. Bazarian** suggested that there could be barriers to implementation of Return-to-Learn curriculum. He claimed that parents often take their kids to the emergency department of their local hospital and that a representative from an ED might be able to illuminate the conversations BIANYS is hosting.

M. Kaplen brought up a question about the charge of the Council as it specifically relates to concussion management. **M. Gnozzio and S. Casscles** clarified that there was an amendment to the Council legislation – specifically, subsection IV within the Council legislation. This allows the Council to convene a committee to produce reports on concussion management which would be presented back to the TBISCC.

M. Kaplen indicated that this item should be placed on the next meeting agenda for further discussion. **S. Casscles** agreed to send the legislation to **M. Kaplen**. **M. Davison** shared that he was involved in a concussion management initiative under a previous chair of the TBISCC. He reported that it was chaotic and the committee stopped working on concussion management because they felt they did not have adequate expertise on the subject. **M. Kaplen** suggested contacting Dr. Hess, who had been involved in a prior concussion management initiative with the TBISCC. **E. Reardon** indicated that BIANYS is open to bringing all interested and appropriate parties into their initiatives.

P. Novak asked about work with parents and brain injury patients so that they know what to expect when working with districts. **C. Bolton** shared that BIANYS works to educate parents and school districts in their community outreach. **P. Novak** offered that many parents do not know what to expect or what they can ask for in an IEP and that school districts are scattered in the appropriateness of their follow-up. **Dr. Bazarian** indicated that there are checklists available for schools. **M. Kaplen** expressed that school districts cannot

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	<p>be counted on to advocate for students, as the services are expensive. Parents should be prepared to advocate for their children.</p>	
<p>Review/Update To-Do List from April 4, 2019 Meeting</p> <p>Prior Authorization</p>	<p>M. Kaplen inquired as to whether or not BIANYS has done any work with repatriation, as that is of interest to the TBISCC. C. Bolton deferred to Peter Kahrman, who has been working with BIANYS on issues of out of state placements. P. Kahrman shared that BIANYS sent a proposal to the TBISCC regarding repatriation. He continued, sharing that his organization (Kahrman Advocacy Coalition) is aware of one person who has died out of state without being able to return to New York. He referenced New York State Senate Bill S4085 regarding services available to people who sustain a traumatic brain injury after the age of twenty-one. P. Kahrman affirmed that Kahrman Advocacy Coalition’s stance (2019-2020 session) on such bill is that it should include anyone who acquires a disability.</p> <p>Simeon Goldman (Disability Rights NY) added that his organization has been monitoring skilled nursing facilities (SNF) in Massachusetts. They have found that a large percentage of residents in SNFs in Western Massachusetts are New York residents. In their opinion, the issue is with a lack of housing for people who are over the age of 22 and have TBI. C. Hymowitz brought up the issue of insurance coverage for brain injury and difficulty getting rehabilitation and funding for proper care. C. Hymowitz requested further discussions on provision of services for individuals who do not qualify for waiver services. The scope of the discussions should include “life after waiver services”. M. Kaplen pointed out that time is limited and that the TBISCC can only cover so much ground in a meeting. He invited DRNY to present on repatriation at the next meeting of the council. He also shared that the TBISCC made a recommendation on insurance coverage in the past that he vowed to produce for the review of the Council.</p> <p>P. Kahrman returned to the issue of the trust fund that was proposed by BIANYS in their presentation, wondering what entity would oversee the administration of the fund. E. Reardon indicated that they are working with many different departments and that oversight of the proposed trust fund is unclear at this point.</p> <p>NYSDOH presented on prior authorization process for placement in out of state nursing facilities, as requested at the April 4, 2019 meeting. M. Davison asked if it was necessary to exhaust the list of NYS facilities prior to moving out of state. S. Goldman asked whether referrals come from out of state SNFs. A conversation ensued regarding reasons people might choose to go out of state rather than to an in-state facility. M. Kaplen brought the conversation back to state responsibility to oversee out of state facilities. S. Goldman reported that SNFs shared that they are asked to prepare a report for NYS and that NYS has never requested that report. C. Hymowitz posited that the issue is that the federal government does not fund housing for people with a disability anymore and instead focus on aging. People are left to find housing on their own. He suggested offering a tax credit for the development of housing for people with disabilities. B. Gnozzio brought up a collaboratively developed house in Ulster County as an example of creativity in solving the issue of inadequate housing stock. P. Kahrman expressed an interest in inviting the people who started the house and are currently living in it to present to the TBISCC. M. Davison</p>	

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Money Follows the Person	<p>presented capacity of agencies to care for people as the real problem. There was general agreement on the TBISCC that wages are an issue with staff retention and recruitment in the direct care sector. P. Kahrman asked the Council for a reason why NYS has not developed a functioning repatriation program. M. Kaplen requested that P. Kahrman send him a comprehensive list of his questions so that they can be presented to the NYSDOH.</p> <p>S. Agnello presented information about the Money Follows the Person program. A call-in participant expressed that in her experience, social workers in out of state facilities do not ask residents whether or not they want to return home as required. The group agreed that could be an issue causing people to stay out of state against their wishes.</p>	
Break for lunch 12:15 pm – 1:25 pm		
EMS Presentation/ Discussion	<p>Ryan Greenberg, Director, Bureau of Emergency Medical Services, presented to the group on EMS protocols in NYS as they relate to people who have suffered a traumatic brain injury, as well as the new basic life support protocols which will be in effect August 1, 2019. Following a discussion, the TBISCC recommended that B. Feuz review the protocols. Mr. Feuz is seeking a letter of support from the TBISCC as an introduction to the various regional EMS advisory groups in order to present issues related to protocols and TBI.</p>	
TBISCC Member/Guest Updates	<p>M. Kaplen requested that NYSDOH collaborate with the chair and co-chair on agenda items. B. Gnozzio suggested that the close of each meeting include a discussion of agenda items for the subsequent meeting. M. Kaplen offered to review previous discussion topics to bring back up to the TBISCC for future exploration.</p> <p>Jennifer Semonite shared that ACCESS-VR is holding public forums for people to talk about their experiences with the program. They will also be updating some sections of the State Medicaid Plan which will require public hearings and public comment. She will send the information to NYSDOH to disseminate to the group.</p> <p>Vicki Clingan offered that the Justice Center will be holding community-based events. A NYSDOH representative agreed to disseminate information.</p> <p>Earl Schmidt from Veterans Affairs announced that he will be working from Buffalo and will receive referrals from 31 regions directly sent to his office. He shared that the VA will be reassessing 200,000 veterans due to new protocols and scans. He suggested a presentation from the VA for the Council at some point.</p> <p>C. Hymowitz requested that NYSDOH present on advance home health care at the next TBISCC meeting. M. Davison asked about subcommittees. M. Kaplen requested that members submit suggestions to the group for subcommittees.</p>	
Adjournment	<p>M. Kaplen introduced a motion to adjourn which was seconded by C. Hymowitz. The meeting was adjourned at 2:39.</p>	