## **Traumatic Brain Injury Services Coordinating Council**

# Meeting Minutes December 12, 2019; 10:30 am – 3:00 pm One Commerce Plaza, 99 Washington Avenue, Albany, NY 16th Floor, Conference Room 1613

| Topic  | Discussion   | Action/Next<br>Steps/Who/When |
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| Attendance   | Council Members Present: Nina Baumbach, Megan Clothier, Michael Davison (Vice Chair), Cliff Hymowitz, Michael Kaplen (Chair), Paul Novak, Earl Schmidt, Dr. Jeffrey Bazarian, Brent Feuz, Crystal Collins, Maxine Smalling (via phone), Jennifer Semonite, Lana Earle  |                               |
|  | Council Members absent: Kenneth Ingenito   |                               |
|  | <b>DOH Staff:</b> Beth Gnozzio, Madeline Kennedy, Andrea Juris, Tom Rees, Fern Fletcher, Tricia Curley, Carla Nazaire, Stephen Casscles, Esq. (Division of Legal Affairs)  |                               |
|  | <b>Members of the Public:</b> Peter Kahrmann, Kim Lawrence, Mary Eisenhauer, Sim Goldman, Joe Abdulla, Nan Paek-Zobel, Anne Marie Todd, Joanne Scandale  |                               |
| Welcome and Introductions                                      | The meeting was called to order at 10:34 am by TBISCC chair, <b>M. Kaplen</b> , who presided over the meeting. The council members introduced themselves and member <b>M. Smalling</b> attended by phone.  |                               |
| Review and<br>Approval of<br>9/26/19 TBISCC<br>Meeting Minutes | M. Kaplen presented the minutes from the September 26, 2019 TBISCC meeting. C. Hymowitz motioned to accept the minutes; E. Schmidt second the motion. Minutes approved unanimously. A draft letter introducing B. Feuz to the various regional EMS Councils as a TBISCC council member supporting his participation at the Regional EMS Council Meetings was presented and approved; M. Kaplen inquired about the use of video and voice webcast since M. Smalling called into the meeting. S. Casscles clarified that a voting member of the Council must be able to see and be seen by all the other members of the Council who are present in order to establish the number for a quorum and to vote. M. Kaplen recommended webcam transmission, both audio and video, should be available for all Council meetings in order to encourage more public participation. He suggested that the Department of Health consider broadcasting the TBISCC meeting more widely. A representative from NYSDOH indicated that the number of available sites for transmission historically has been limited to specific NYS locations. The IT department would be contacted to determine if the NYSDOH webinar software is compatible with offsite computers and if there is sufficient bandwidth to meet the request. |                               |
| Charge of the Council  | S. Casscles, Esq. discussed the charge and mission of the Council, long range objectives, section 2740 of the Public Health Law, and NYSDOH responsibility to coordinate policy. M. Davison summarized the TBISCC charge as: the TBISCC role is to share expertise and evaluate needs, make recommendations to NYSDOH. NYSDOH assesses the suggestion, may add specific details, researches the item and takes action as appropriate. B. Feuz asked when the definition of TBI in Public Health Law was last updated. S. Casscles stated it was updated in 2014 with the amendment to add Concussion Management. M. Kaplen voiced a concern that recommendations made by the Council and sent to NYSDOH have not been acted upon, nor has information on the status been brought back to the Council. B. Gnozzio   |                               |

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| clarifies that this is a documented process and recommendations must be brought forth to the NYSDOH            |
| by a formal written resolution. <b>B. Gnozzio</b> indicated that she would conduct a search of past minutes of |
| the council and report on the status of any resolutions made by the Council.                                   |

#### Home and Community-Based Services Setting Rule

**Madeline Kennedy** was introduced to the Council for her presentation on the Home and Community-Based Services (HCBS) and Final Rule.

A copy of the PowerPoint presentation was distributed to the TBISCC members and public affiliates.

- **M. Kennedy** presented the federal definition of Home and Community-Based Services (HCBS) as related to the settings rule as the opportunity to optimize individual initiative, provide autonomy and independence with choices for service recipients. She also discussed two types of assessments required by CMS for setting compliance, and the required site level reviews. She acknowledged there are differences in the various regions throughout the state and how different reviews may be implemented. **M. Kennedy** also discussed the "Heightened Scrutiny" assessment process and the associated timeline to complete reviews by 2021. There are different stages of the process with varying completion dates and full compliance is required by 2022.
- **C. Hymowitz** shared that in his experience, Rapid Housing and Olmstead Housing work well for TBI clients. **B. Gnozzio** explained that the HCBS settings rule applies to: TBI waiver housing; Structured Day Programs; and other settings such as OPWDD day habilitation programs and managed care social day programs. **M. Kaplen** expressed that most people who have acquired a TBI do not receive any TBI services from the state because they are not Medicaid eligible. He presented that NYSDOH should develop TBI services through Medicaid or other state resources, for all people with a TBI and it should be a priority for the Department. **B. Gnozzio** presented that perhaps the Council may want to seek to develop a resolution requesting services comparable to Medicaid services but that they should be available through health insurance, private pay and third-party insurance, not just Medicaid. **M. Kaplen** stated that he believes that the NYSDOH should continue to move forward to ensure these services come to fruition for all individuals with a TBI. **C. Hymowitz** presented the example that the Managed Long-Term Care (MLTC) benefits package is not equipped to help the TBI population either and would like to recommend that MLTC plans develop services specific to the TBI population.
- **C. Hymowitz** also stated there are not enough options for housing. **B. Gnozzio** agreed and presented that TBI waiver housing is a limited resource, but is compliant with HCBS settings requirements. Waiver participants may not reside in a congregate care setting and receive waiver services.

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| National Center on | C. Hymowitz and M. Clothier presented information on the National Center on Advancing Person-  |                   |
|--------------------|--|-------------------|
| Advancing Person-  | Centered Practices and Systems (PCP). In conjunction with the person-centered plan, they want to bring   |                   |
| Centered Practices | attention to the differences between waiver services as related to the level of functioning of the waiver  |                   |
| & Systems TBI      | participant. They presented their position that the higher functioning the person is, there are fewer  |                   |
| Initiative         | services available to waiver participants. This issue goes beyond just waiver services. Generally, high  |                   |
|                    | functioning survivors with more cognitive and psychological issues face new challenges and need a  |                   |
|                    | different set of strategies and services than survivors who are earlier in recovery or are medically or  |                   |
|                    | physically challenged. The current suite of services is aimed at people who are earlier in recovery or who   |                   |
|                    | are not as high functioning. M. Clothier and C. Hymowitz feel that a second set of services should be  |                   |
|                    | introduced to provide ongoing support to people who are higher functioning TBI survivors. They would like  |                   |
|                    | NYSDOH to adopt the new model Person-Centered-Planning (PCP) approach to address this type of  |                   |
|                    | service provision. <b>M. Kennedy</b> stated NYSDOH currently has training opportunities which she will discuss   |                   |
|                    | further with <b>M. Clothier</b> and <b>C. Hymowitz. M. Kaplen</b> stated that this is important information for the  | nydohpcptraining. |
|                    | NYSDOH to receive as well as for the public at large. He states it should be publicly accessible and   | com/events        |
|                    | request that it be posted on the NYSDOH website. <b>B. Gnozzio</b> informed the Council that it will be posted with the meeting minutes and will be available on the Department website. <b>A. Juris</b> shared that the |                   |
|                    | Person-Centered Planning initiative is underway. NYSDOH is in the process of creating a resource library   |                   |
|                    | to be posted to the NYSDOH website and would like <b>C. Hymowitz's</b> and <b>M. Clothier's</b> presentation to be   |                   |
|                    | included. <b>C. Hymowitz</b> and <b>M. Clothier</b> are working to arrange/serve as liaison(s) between the New York  |                   |
|                    | Person-Centered Planning initiative, the National Center on Advancing Person-Centered Practices and  |                   |
|                    | Planning and TBI survivors. They are seeking to enhance protocols and training for self-directed team  |                   |
|                    | meetings and self-assessment practices in order to have more control over their service plans. <b>T. Rees</b>  |                   |
|                    | and C. Nazaire will work with C. Hymowitz and M. Clothier on this project. A. Juris presented that   |                   |
|                    | Public Consulting Group (PCG) and NY Alliance Learning Institute initiatives include training events for   |                   |
|                    | person-centered plan development, training for managers and how to develop "person-centered thinking"  |                   |
|                    | for service providers. P. Novak asked how the training could be expanded to non-Medicaid providers and   |                   |
|                    | stakeholders. He believes this type of training should be available to all different types of care providers.  |                   |
|                    | C. Hymowitz asked if a vote is needed to develop a workgroup for this project, M. Kaplan indicated this  |                   |
|                    | is not required, that "he" can appoint members, and welcomed C. Hymowitz and M. Clothier to submit a   |                   |
|                    | committee report at the next meeting.  |                   |
| Break for lunch    |  |                   |
| Out-of-State       | M. Kaplan welcomed representatives from the Kahrmann Advocacy Coalition (KAC) including P.   |                   |
| Repatriation and   | Kahrmann, K. Lawrence, M. Eisenhauer and S. Goldman, Esq. P. Kahrmann presented that a main  |                   |
| Stakeholder        | complaint of those with a TBI is being spoken to like a child. The second is not being heard. Each TBI   |                   |
| Planning and       | survivor provides their personal experience with TBI. Many hard-to-serve individuals with a TBI often are  |                   |
|                    | placed in out-of-state facilities and repatriating home becomes a problem, almost impossible. This is due  |                   |
|                    | in part that currently there is no repatriation plan for New York State. P. Kahrmann also suggested that   |                   |
|                    | there is discrimination against individuals with a TBI accessing services (it is offered through the   |                   |

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Developmental Disabilities service system but is restricted by the twenty-two (22) year old age limit associated with the age of onset for the disability). S. Goldman clarified that legally the regulation is not discriminatory, but individuals may be excluded from services due to the requirement. P. Kahrmann stated that New York State needs to take a fresh start to address this service need. He presented that multiple out-of-state facilities have an occupancy rate consisting of primarily New York State residents. In some cases that enrollment is over eighty percent (80%). He stressed that these people are often forgotten and are subject to poor quality of life and only maintenance care. **P. Kahrmann** indicated that he seems to just continue to attend multiple Council meetings where the problem is discussed but no action is taken. In 2018, KAC submitted a Repatriation Plan to this Committee and NYSDOH and nothing happened. K. Lawrence questioned what happens to people like M. Eisenhauer's son, who has a TBI, when his parents die? Who will care for them when they are left alone? M. Kaplan stated he thought a written proposal was submitted to NYDOH for further discussion. B. Gnozzio stated that it was discussed at a meeting but that no action had been taken because a formal resolution had not been submitted by the TBISCC to the NYSDOH. B. Gnozzio stated she will check the records to confirm and explained that the Council needs to define the service models and services it wishes to present and be clear about the details they are recommending to the Department, M. Davison presented that the Council needs to change the way it wants to move issues forward or nothing will ever change. He suggested that S. **Goldman** develop a formal recommendation for the Council to consider and adopt for presentation to NYSDOH. M. Kaplan indicated that the sub-committee must define its expectations considering the limited resources available to meet this important need. He reminded the Council that there is no staff available to dedicate to this type of initiative. M. Davison suggested the Council develop a taskforce to further develop a plan. M. Kaplan responded that this would only further strain the existing resources and Council members. B. Gnozzio suggested to P. Kahrmann that perhaps he could present a more defined model/plan to NYSDOH, which identifies what services and resources are needed for its implementation. M. Davison agreed and recommended that the workgroup present ideas which will implement change for TBI survivors, and the Council will present it to NYSDOH. M. Kaplan reiterated to P. Kahrmann to lay out a plan, with bullet points, and legal arguments to make a clear concise request.

S. Goldman will work with P. Kahrmann and TBISCC to develop a formal resolution for TBI/NHTD Repatriation.

- **P. Kahrmann** suggested that it would be helpful to further educate people about the various housing and service options that may be available and suggested the Council have representatives from OPWDD, OTDA, Housing, and OASAS to present at future Council meetings and share their experiences.
- **B. Gnozzio** opened with a PowerPoint presentation which provided historical background to address and answer stakeholder questions presented by **KAC. M. Kaplan** stated that the information did not meet his standard for presentation and stated the information was not presented in the correct format. The presentation was terminated, and the Council moved on to the next item on the agenda.
- **B. Gnozzio** stated she will submit the questions with answers with meeting minutes.

#### Concussion Management

#### Current members: Dr. Bazarian, B. Feuz, C. Hymowitz, P. Novak

**S. Casscles** stated that the committee can appoint members and make recommendations such as public awareness, academic research, and development outreach; members agreed that meetings could be done electronically. Formal meeting minutes do not need to be maintained, but meeting discussions

**Dr. Bazarian** will forward Emily Childs' information to DOH.

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|                | should be documented. Various experts in the field can provide guidance to the committee but do not have to be sub-committee members. It was decided that Emily Childs, Regional Education Coordinator at the Defense and Veterans Brain Injury Center at Fort Drum, will be invited to future meetings. <b>Dr. Bazarian</b> stated there needs to be clarity regarding the charge of the committee. It appears that the Council has already completed work on this issue and effort should not be duplicated. <b>B. Gnozzio</b> presented that that the scope of the subcommittee can be as large or small as the members determine; committee meetings can be held outside of the time allotted for Council meetings and recommendations can be presented to the Council. <b>Anne Marie Todd</b> is also interested in also becoming a subcommittee member. | C. Hymowitz will research what is in the Concussion Management Bill and work with C. Nazaire of DOH to research what other states are doing and provide to the TBISCC. |
|----------------|---|--|
| Member Updates | <b>C. Hymowitz</b> indicated that he was disappointed with <b>Access VR</b> as he saw no acknowledgement that October was National Disability Employment Month. <b>J. Semonite</b> responded that the information was posted on their website under the Business Relations tab. <b>C. Hymowitz</b> requested that in the future this information have a broader announcement to stakeholders and constituents. <b>C. Hymowitz</b> requests DOH review and support Bill # S6447 (Discrete Disability Designation).   |  |
| Public Comment | M. Davison inquired if there were any further questions or comments, to which the response was "no."  |  |
| Adjournment    | M. Davison motioned to adjourn the meeting at 2:44 pm. It was seconded by E. Schmidt.   |  |