**Traumatic Brain Injury Services Coordinating Council**

**Meeting Minutes**

**Monday, September 30, 2013**

**10:30am – 3:30pm**

**Empire State Plaza, Concourse Level, Meeting Room 125**

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| **Attendance** | Present: Barry Dain, Timothy Pruce, Judith Avner, Nina Baumbach, Michael Kaplen, Lydia Kosinski, Chad Cook, Anne Sternback, Joseph Vollaro, Colleen Scott  
Absent: Megan Clothier, Michael Davison, Kenneth Ingenito, Barry Jordan, MD, Meredith Klein, Cher Montayne, Lisa Robateau-Epps  
Ad-hoc Members Present: Ann Marie Calabrese  
DOH Staff: Helen Hines, Tricia Gorman |  |
| **Welcome** |  
- The meeting was called to order; Barry Dain presided over the meeting.  
- The meeting agenda was reviewed.  
- Barry Dain acknowledged Cheryl Veith for all of her work on the council.  
- A quorum was not present, therefore it was noted that no voting could be done at this meeting.  
- A suggestion was made by Colleen Scott to change the 5/31/13 minutes as their contract is with Disability Rights New York, not the Justice Center. **The 5/31/13 minutes have been edited.** |  |
| **Managed Long Term Care Presentation** | Margaret Willard, Interim Director, New York State Department of Health Bureau of Managed Long Term Care  
The council had a comprehensive presentation given by DOH staff on Managed Long Term Care with a handout. Among the points made were:  
- As of 9/1/13 there a total of 114,815 enrollees in MLTC, the majority being in the partial capitation plans  
- To date there are 27 partial cap plans; 8 PACE plans and 10 Medicaid Advantage plans  
- Persons now enrolled in the NHTD and TBI waivers will be among the last to transition to MLTC. This allows time to address ongoing issues such as housing needs for this population | During discussion questions were raised about "coding issues" which are being addressed but with some continuing to be problematic |
| **UAS-NY Presentation** | John Russell, UAS Project Director; Scott Jill, UAS Program Coordinator  
UAS is a software system housed inside the New York State Department of Health’s Health Commerce System. It is not diagnostic in nature, but is a needs assessment. UAS was created by a company called InterRAI. UAS is in the midst of a statewide rollout that started in May 2013 and will be completed in February 2014. The assessment will be implemented by region with the first region being completely implemented October 1, 2013. The TBI waiver program will be using the UAS to determine level of care for its participants.  
John Russell explained it is a tool for all ages with distinct categories of 0 – 3; 4 – 17; and 18 & older. |  |
### Topic Discussion

Further, there are “boxes” in each section, which allows inclusion of written comments as part of a person’s UAS. This tool is only accessible through the State’s Health Commerce System and has further access protections based on an individual’s access assignment or role. For example, an administrator of an agency would likely have an access code different from a case manager and vice versa so that each would have access to designated sites within the system for which they had been approved.

A number of concerns were raised but with a similar focus that TBI population not be “marginalized” within this system and the larger MRT vision recognizing that it is a variable population in terms of disability and service needs – wanted assurance the UAS is sensitive to this.

Members asked for a copy of the UAS but were informed the DOH was not authorized to do so due to the licensing agreement with the company that holds the UAS copyright. Other means of access may be available but not from DOH.

### State Agency Updates

**New York State Education Department (NYSED)-ACCESS-VR – Anne Sternbach**

Reported that changes in Supportive Employment are planned to commence in January 2014. The program will be working on enhanced outreach to high schools to assist more students in the transition from school to work.

**New York State Office for People with Developmental Disabilities (OPWDD) - Nina Baumbach**

- Rate setting functions have moved from OPWDD to DOH. New “BRICK” rate methodology was formed so that rates will change within the overarching MA budget but agencies will have transition time to adjust.
- Front Door Program targeting outreach to families who may be needed services for the first time

**Justice Center for Protection of People with Special Needs – Colleen Scott**

Reported that the former CQC transitioned to the Justice Center in June and that the P & A function was transferred to the Not for Profit Group of Disability Advocates. Colleen’s role is evolving but the Justice Center will continue in advocacy work but the details of how are still being developed.
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| **Department of Health (DOH) – Lydia Kosinski/Helen Hines**  
Lydia Kosinski - A report of the TBI Waiver was given. Current data shows there are 2888 persons enrolled in the waiver with 297 providers participating. 1000 persons receive the Housing assistance. Discharges from the program have lowered in comparison to new enrollments. CMS has extended the waiver until December of this year and discussion continues with the goal of extending it further.  
A guidance letter was transmitted in August to clarify the role of service coordinators when a fair hearing is brought involving a TBI waiver participant. The letter did not make a material change but rather explained the parameters of the acceptable role for case managers in such situations.  
| Helen Hines - The HRSA grant continues with implementing the recommendations of the TBI Action Plan. Since June, work has included:  
- Drafting TBI content for the DOH website that is to be more informative and user friendly. It is now under DOH review.  
- Protocols for EMS professionals was focus of a day long discussion among experts in this field which resulted in the HRSA Grant Staff drafting suggested protocol with evidence based sources and submitting it to the Bureau of EMS. The protocol is based on one written by Brent Feuz, a former EMT and brain injury survivor and Dr. Antone Hardy. A handout for EMS and physicians to give persons was also drafted and under review by DOH. A follow up meeting with experts ifs planned for early December.  
- DOH applied for and received a national Community of Practice Grant that focuses on TBI in children. There is no funding attached but it provides access to best practices of the other 15 state grantees.  
| **New Business**  
Committee Work- Barry Dain suggested the formation of new committees to work on particular topics. They are:  
1. Repatriation Committee/MRT Committee. The purpose of this committee is to work on removing or overcoming barriers to repatriation. Joseph Vallaro volunteered to chair this committee. Timothy Pruce, Traci Allen, Karen Thayer, and Nina Baumbach volunteered to serve on the committee.  
2. Education/Training Committee. The purpose of this committee is to help identify the training needs of providers and to fill in training gaps. The committee will also help to educate the public |
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<td>and in schools regarding brain injury. Barry Dain volunteered to chair this committee. Traci Allen volunteered to serve on the committee.</td>
<td>3. <strong>Membership committee</strong>. The purpose of this committee is to monitor Council membership and prevent any tardiness in reinstatement of members. Barry Dain volunteered to chair this committee. Colleen Scott and Timothy Pruce volunteered to serve on the committee. No quorum was present therefore the Council tabled voting on committees.</td>
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<td><strong>TBI Trust Fund Proposal</strong>- The purpose of the TBI Trust Fund would be to assist individuals with Traumatic Brain Injury who are not otherwise eligible for services as a payer of last resort. The Trust Fund will provide funding for services and supports to individuals with TBI. Several other states have TBI Trust Funds. The Council is looking closely at the New Jersey TBI Trust Fund to serve as a model. Different funding sources were discussed as well.</td>
<td><strong>Bylaws Draft Revision</strong>- No quorum was present therefore the Council tabled voting on the bylaws.</td>
<td><strong>Next meeting</strong>- presentation of each state’s TBI Trust Fund</td>
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<td><strong>Public Commment</strong></td>
<td>Brent Feuz- TBI survivor and EMT. He is working on a comprehensive protocol on how to treat TBI. He stated that it will be a roadmap for treating brain injury. He stated that they are working on a protocol for first responders and doctors in order to establish a standard of care for brain injury. This will include specific training for first responders. He stated that the program will include sheets on signs and symptoms to watch for and where to get help to be given to those who present to the ER with a brain injury. The program will also include giving a listing of support groups, and Public Service Announcements regarding TBI.</td>
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<td>Kim Lawrence- Stated that she was told that people are not being repatriated back to NYS due to lack of resources. She would like the council to get confirmation of this statement. She also asked if a response was received for Dr. Shah regarding a letter sent in February 2013. The council will request a response.</td>
<td>A formal request was made to make the TBISCC meeting accessible to those who are unable to travel to Albany. It was also announced that there is now a statewide stakeholder coalition that will be working with DOH.</td>
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<td><strong>Next Meeting</strong></td>
<td>• The next meeting was planned to be held March 3, 2013 but the Council requested an earlier date to meet again. DOH staff indicated they would look into that and try to schedule an alternate date earlier in the year. The meeting was adjourned.</td>
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