

# Traumatic Brain Injury Services Coordinating Council

## Meeting Minutes

**Friday, June 20, 2014; 10:30am – 3:00pm**

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

Topic	Discussion	Action/Next Steps/Who/When
<b>Attendance</b>	<p><b>Present:</b> Nina Baumbach, Sal Cerniglia, Barry Dain, Michael Davison, Michael Kaplen, Lydia Kosinski, Cher Montanye, Lisa Robateau-Epps, Colleen Scott, Anne Sternbach, Joseph Vollaro</p> <p><b>Absent:</b> Megan Clothier, Kenneth Ingenito, Meredith Klein, Timothy Pruce</p> <p><b>Ad-hoc Members Present:</b> Ann Calabrese, Chad Cook</p> <p><b>DOH Staff:</b> Helen Hines, Lavonda Howe, Dawn Wiese, Scott Jill, John Russell</p>	
<b>Welcome and Introductions</b>	<ul style="list-style-type: none"> <li>• The meeting was called to order; Barry Dain, Chair, presided over the meeting.</li> <li>• Sal Cerniglia is the new Council state representative from the NYS Office of Mental Health.</li> <li>• The 9/30/13 and 4/10/14 meeting minutes were reviewed. The 9/30/13 minutes were accepted pending a change be made to the name for the NYS Office for People with Development Disabilities.</li> <li>• A conference call was initiated for those interested parties unable to attend in person.</li> </ul>	
<b>Brent Feuz – Guest Speaker</b>	<ul style="list-style-type: none"> <li>• Brent is a TBI survivor who was injured in the line of duty as a Firefighter/Paramedic.</li> <li>• The presentation focused on a protocol that Brent has been developing with assistance from Anton Hardy, Ph.D., Psychologist, for first responders in treating mild/moderate brain injuries. Helen Hines, TBI Grant Coordinator, Department of Health (DOH), and the Brain Injury Association of NYS (BIANYS), have also assisted in the development of the protocol.</li> <li>• The protocol is designed to be placed into first responder protocol books and contains the symptoms of brain injury, a checklist of symptoms, an illustration of optimal treatment of brain injury, as well as a description of provider specialties.</li> <li>• The protocol has been submitted to the DOH’s Emergency Medical Services Bureau and is currently awaiting review.</li> <li>• The “Proposed Comprehensive Multi Agency/Organization Response to Brain Injury” is still being enhanced with additional information.</li> <li>• BIANYS will be assisting with distributing protocol notebooks to TBI support groups throughout New York. The notebooks will also contain a Lifeguide, which will contain information on non-medical services/supports available. The notebooks will be paper format, as well as available electronically.</li> <li>• Once/if the protocol is approved, the hope is to have in-services for medical personnel, and in the long term to have the protocol available in the school setting (i.e. part of CPR training). A long term goal is also to have the Department of Health provide public service announcements to help increase the number of individuals who receive care following their injury.</li> <li>• Brent asked the Council to review the materials presented and to provide feedback/input to enhance the content.</li> </ul> <p><u>Questions/Comments:</u></p> <p><b>Cher Montanye (OASAS):</b> Has there been any consideration for protocols for patients that overdose, as people may not realize there is a brain injury involved?</p> <p>Answer: Only secondarily; first responders are treating what they see, which is the brain injury. Ideally, future training will focus on underlying conditions.</p>	<p><b>2 Handouts:</b></p> <ul style="list-style-type: none"> <li>- “Proposed Protocol for Mild/Moderate Brain Injury in New York State”</li> <li>- “Proposed Comprehensive Multi Agency/Organization Response to Brain Injury”</li> </ul>

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	<p><b>Mike Nicholson (public):</b> The Rochester TBI Association Support Group has reviewed the protocol and fully supports it.</p> <p><b>Joanne Scandale (public):</b> Once/if the protocol is adopted, will there be an effort to look back at other protocols (i.e. heart attack, overdose) and have some of the references in the brain injury protocol tied to the other protocols?</p> <p>Discussion: Brent would like to get his protocol established and then have it tie into other areas, such as Worker’s Compensation, No-Fault, and then work it into other areas and re-look at all protocols.</p> <p><b>Lois Tannenbaum (Board President/Brain Injury Association of NYS):</b> Recently the discussion of non-traumatic brain injury (i.e. acquired BI) has been a big focus and it is important that existing protocols apply to all types of brain injury, not solely TBI.</p>	
<p><b>TBI HRSA Grant Update</b></p>	<p><b>Helen Hines, NYS Department of Health, TBI Grant Coordinator</b></p> <ul style="list-style-type: none"> <li>• The current TBI HRSA (Health Resources and Services Administration) grant cycle ends June 2014, and resulted in the following accomplishments: <ul style="list-style-type: none"> <li>○ Development of the state’s TBI Action Plan (available on the DOH’s website). DOH has begun implementing 18 of the 29 recommendations in the plan.</li> <li>○ Creation of a booklet on the TBI Waiver Program (available on the DOH website).</li> <li>○ Update of TBI information on DOH website, including the listing of TBI specialists/resources.</li> <li>○ Creation of a TBI Symptom card, which is awaiting formatting by DOH’s public affairs office.</li> <li>○ Assisted Brent Feuz with his TBI protocol.</li> <li>○ DOH issued multiple press releases related to TBI.</li> <li>○ Collaborated with BIANYS on multiple efforts: 26 webinars held; 2 DVDs created about veterans with TBI; 1 DVD created about families with children with TBI; BIANYS has been training school personnel on concussion; 6,000 sports related concussion information packets produced by the CDC have been distributed statewide; BIANYS revised the curriculum for professionals, “Understanding Life with Brain Injury”, and approximately 1,200 individuals have been trained.</li> </ul> </li> <li>• The TBI grant was just approved for an additional 4 years of funding to continue working on recommendations in the Action Plan. DOH will continue its collaboration with BIANYS, and also collaborate with Albany University’s School of Public Health. The 4 goals of the grant are: <ol style="list-style-type: none"> <li>1. Develop curriculum for emergency personnel to ensure proficiency in mild/moderate TBI, with the objective of training 1,500 personnel by the end of the grant.</li> <li>2. Institute a Train the Trainer Program: BIANYS will adapt their current curriculum for identifying a TBI to 3 audiences: school personnel, to include guidance counselors, nurses, and teachers (objective is to train 1,400 staff); staff in early childhood programs (objective is to train 600 staff); and staff in domestic violence shelters (objective is to train 200 staff).</li> <li>3. Develop a comprehensive web based directory of TBI related services and providers (objective is to have 200,000 views/hits on the web).</li> <li>4. School of Public Health will develop 2 TBI related training curriculum. One for doctors and nurses, and one for medical and nursing students (objective is to train 15,000 individuals).</li> </ol> </li> </ul>	

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	<p>Comments:</p> <p><i>M. Kaplen:</i> Concern that the proposed grant activities have been discussed in the past and have gone nowhere. Hopeful that with DOH’s endorsement the goals of the grant are achieved and that the Council becomes an active liaison for continuous input on grant activities.</p> <p><i>J. Vollaro:</i> The need for TBI related training has been a constant theme; the Council has an education committee, therefore suggested that Helen work with the Council to avoid duplication of work.</p>	
<p><b>NYS Uniform Assessment System (UAS) Discussion</b></p>	<ul style="list-style-type: none"> <li>• Guests: John Russell and Scott Jill of the DOH UAS-NY Project Team were present to answer questions regarding the UAS.</li> <li>• J. Vollaro provided his opinion of how the UAS is being used, as well the issues surrounding its use.</li> <li>• The UAS is currently being co-administered with the PRI for the TBI waiver program, as the UAS has not been approved by CMS as the sole assessment tool for determining level of care eligibility.</li> <li>• Certain Council members have concerns with the UAS: it is felt that the tool has not been properly vetted and is not accurately assessing individuals with all types of cognitive disabilities, not solely TBI; and members feel that failure to implement an accurate assessment will result in individuals being deemed ineligible for services.</li> <li>• M. Kaplen: requested that a discussion of the UAS be added to this meeting’s agenda as a request was made by the Council 2 meetings ago that the UAS be shared, however was told that the tool is proprietary and could not be shared. At the end of today’s meeting, a formal request will be made to receive the tool, as well as studies used by DOH to validate its use among individuals with acquired brain injuries. The use of this tool becomes a civil rights issue when individuals with brain injuries are deprived of services.</li> <li>• L. Kosinski: the DOH intends to use the UAS for the following programs: Adult Day Care; Assisted Living; Personal Care; Consumer Directed Personal Assistance Program; Care at Home Waiver; Long Term Home Health Care Program; Nursing Home Transition and Diversion Waiver Program; TBI Waiver Program. The tool is not a diagnostic tool and is not targeted to any specific condition.</li> <li>• Vicky and Jonathan Mueller (Mother and TBI survivor): V. Mueller expressed her concerns with the UAS as the assessment tool for the TBI waiver and would like the UAS to be respectful of individuals with brain injury. She discussed her son Jonathan’s disabilities, reviewed the results of his UAS assessment and how the tool did not capture the level of care that Jonathan requires. Jonathan’s overall score on the UAS was a 1, deeming him ineligible for nursing home level of care. Jonathan provided a statement about how he benefits from the TBI waiver program.</li> <li>• There is a concern that UAS assessors are not receiving information from all of the parties necessary to provide an accurate assessment of the individual. Concern that individuals assessed are not provided with a way to appeal the results of the UAS.</li> <li>• The council requested a copy of the UAS scoring sheet. Per the DOH UAS-NY Project Team, the scoring sheet is an algorithm embedded into a software program.</li> <li>• Any specific questions on the UAS can be directed to the <b>UAS mailbox: UASNY@health.state.ny.us</b></li> </ul>	<p><b>A copy of Jonathan’s UAS was shared with the Council.</b></p> <p><b>J. Russell stated that he will look into getting the scoring protocol for the council.</b></p>

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<p><b>NYS Uniform Assessment System (UAS) Discussion, continued</b></p>	<ul style="list-style-type: none"> <li>• Due to a poor phone line for the meeting, individuals can submit questions about the Council’s discussion to the <b>TBI mailbox: TBI@health.state.ny.us</b></li> <li>• AnneMarie Todd (TBI survivor): A. Todd provided a statement to the Council about herself and her experience with the UAS assessment. She stated that the assessor did not ask any questions about TBI, her cognitive or mental health, all of which severely impact her life. AnneMarie stated that the TBI waiver program has greatly enhanced her life and without it would result in a decrease in her quality of life.</li> <li>• Traci Allen (Executive Director, The Alliance of TBI and NHTD Waiver Providers): The Alliance has a statewide membership of providers participating in the TBI and/or NHTD Waiver programs, with a current focus on Managed Long Term Care and Medicaid Redesign. Ms. Allen provided statistics from a provider survey completed in April related to the UAS implementation. The Alliance is not opposed to a uniform assessment tool, however the tool needs to accurately assess cognitive disabilities. The Alliance asked the Council to formally request that the UAS not replace the PRI/Screen for the TBI waiver until more work has been done to identify the deficits of the tool in accurately assessing cognitive deficiencies.</li> <li>• J. Russell: DOH acknowledges that the tool is new and continues to actively look at data. DOH confirmed that the UAS is not a diagnostic tool. Nurses are trained in the use of the instrument, however DOH recognizes that there is a difference between being trained on the tool versus how individuals are trained to be a good nurse (i.e. professional development).</li> <li>• A request was made that DOH utilize the Council and its experts, and requested a list of other states using the UAS for individuals with brain injuries.</li> <li>• L. Kosinski: CMS has granted the TBI waiver program an extension, therefore the UAS will not be utilized until least September 2014.</li> <li>• Kevin Defayette (Residential Resources): stated that while some of the concern with the UAS lies with the assessor, his staff has been present during the assessments and issues are not solely the assessor, but the content of the tool.</li> <li>• Jodi Rappinger (RES Company): shared a TBI waiver participant’s story and how he has benefitted from the waiver program and if he was to lose his services would likely end up incarcerated.</li> <li>• M. Kaplen: initiated 5 formal motions for the Council:             <ol style="list-style-type: none"> <li>1. The Council will formally request a copy of the full UAS tool, including the scoring criteria, copies of all studies utilized by DOH concerning the validity of its use for individuals with TBI, as well as all comparison studies between the PRI/Screen and UAS. (Motion approved)</li> <li>2. The Council will request that DOH performs studies, and shares results with the Council, on the efficacy of the UAS in determining eligibility for TBI related services before implementing the tool in the TBI Waiver Program. (Motion approved)</li> <li>3. The Council will request that DOH consults with the Council, and the Council is an active participant in the development of a final screening tool that accurately assesses individuals’ cognitive abilities when determining eligibility for TBI related services. (Motion approved)</li> </ol> </li> </ul>	<p>The Alliance provided two handouts:                      -Letter dated 4/19/14 submitted to the UAS Team.                      -Letter dated 6/19/14 submitted to Mark Kissinger, DOH.                      The Council requested that any response the Alliance receives from DOH to the letters submitted be shared with all members.</p> <p>Ms. Rappinger provided a copy of the waiver participant’s UAS, as well as his story.</p>

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	<p>4. The Council will request that DOH places a moratorium on the implementation of and use of the UAS in screening any individual with a brain injury. The Council also requests that DOH collects additional information during the moratorium comparing the PRI/Screen and the UAS. (Motion approved)</p> <p>5. The Council will formally request that the Commissioner of the DOH provides a written response to each of the Council's motions within 30 days of submission. (Motion approved)</p>	
<b>Guest/Member Updates</b>	<ul style="list-style-type: none"> <li>• <b>Lois Tannenbaum (Board President, BIANYS; Guest):</b> fully supports all of the motions of the Council and requested that the voice of BIANYS is heard prior to any motions/votes of the Council. Lois expressed her concerns with the UAS and that the unintended outcome of the assessment could be ineligibility for services. Please see Lois's handout.</li> <li>• <b>Sal Cerniglia (NYS Office of Mental Health):</b> OMH is working on Mobile Integration Teams, which focus on re-deploying staff from downsized hospitals into the community. Sal would like to see OMH use Brent's protocol for training staff, and hopes to utilize any information coming through the Council in the work of OMH.</li> <li>• <b>Anne Sternbach (NYS Education Department, ACCESS-VR):</b> NYSED is working with a transition team to provide services across the state. People are not required to be waiver participants in order to utilize ACCESS-VR.</li> <li>• <b>Chad Cook (NYS Department of Financial Services; Ad Hoc Member):</b> The department has been getting in the latest round of NY State of Health submissions and approving insurance forms for next year's Health Exchange. Finalizing language and ensuring the forms are in compliance with federal and state law.</li> <li>• <b>Colleen Scott (Justice Center for Protection of People with Special Needs):</b> Colleen highlighted 2 programs that the Center has: 1) Surrogate Decision Making Committee: a volunteer team that oversees end of life decisions for individuals who may not be able to make those decisions for themselves. 2) TRAIID program (Technology Related Assistance for Individuals with Disabilities). There are 12 TRAIID centers in NYS which helps ensure people have the right equipment they need when transitioning home.</li> <li>• <b>Nina Baumbach (NYS Office for People with Developmental Disabilities):</b> OPWDD has a new acting Commissioner, Kerry Delaney. OPWDD is working towards managed care and piloting an assessment tool to ensure validity and assess all needs of the individuals served. Re-launching the Front Door program to work out kinks in the system to ensure appropriate selection of services.</li> <li>• <b>Cher Montanye (NYS Office of Alcoholism and Substance Abuse Services):</b> OASAS has very little focus on TBI at the moment.</li> <li>• <b>Lydia Kosinski (NYS Department of Health):</b> The TBI waiver program currently serves approximately 3,000 individuals, with the majority in the Rochester region. Working on repatriation; there are currently 26 referrals from out of state facilities. The Money Follows the Person program continues to assist with transitioning individuals into the community. The Fully Integrated Dually Eligible (FIDA) program will begin in downstate regions, serving people voluntarily with an integrated series of services. Other efforts DOH is focusing on: Delivery System Reform Incentive Payment Program (DSRIP), Balancing Incentive Program, Managed Long</li> </ul>	<p>Handout: Lois provided a handout outlining key points of interest and concerns with the UAS.</p>

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	Term Care (MLTC). No definitive date when the TBI and NHTD waiver programs are going into MLTC. Questions related to MLTC can be directed to the mailbox: MLTC@state.ny.us.	
<b>Committee Reports</b>	<p><b>Repatriation Committee:</b></p> <ul style="list-style-type: none"> <li>• A question was raised as to what barriers exist that are keeping people out of state. Answer: anecdotally, individuals that are difficult to serve either behaviorally or physically, and are placed out of state, or they have requested out of state placement to be close to family.</li> <li>• Sal Cerniglia will become part of the Repatriation Committee.</li> <li>• Barry, Joe, Paul Akers and Vicky Mueller participated in a call with CMS regarding the UAS. CMS has asked to be copied on any information presented at the Council.</li> </ul> <p><b>Membership Committee:</b></p> <ul style="list-style-type: none"> <li>• The majority of Council member’s appointments have expired. State agency representatives do not have expirations.</li> <li>• Barry will communicate with each member regarding their expiration; members are responsible for their own reappointments.</li> <li>• There are 2 Council vacancies: 1 Governor appointment for an individual with TBI; 1 Senate Minority appointment for a public representative.</li> </ul> <p><b>Education Committee:</b></p> <ul style="list-style-type: none"> <li>• Working with BIANYS to have a presentation next meeting on what the agency has been working on. The committee structure was approved by the Council.</li> </ul>	<p>Sal was invited to present OMH’s initiatives at the next Council meeting.</p> <p>If Council members have reappointment notices, please provide those to Barry.</p>
<b>Old Business</b>	A discussion of the Council’s By-laws will be an item on the next meeting’s agenda.	The final revised By-laws will be sent out for Council review before the meeting.
<b>Public Comment</b>	Mike Nicolson: TBI survivor requesting that the TBI council write a letter on his behalf to Congress requesting that he be grandfathered in to receive benefits through the Justice Department’s Public Safety Disability Law. Barry will share the correspondence that Mike has sent to the BIANYS with the Council for consideration.	
<b>Next Meetings and Adjournment</b>	The next meeting is scheduled for Friday, September 19, 2014. The location of the next meeting will be determined. The meeting was adjourned. *As of 8/18/14, the next meeting will not be held on 9/19/14 due to a conflict. A new meeting date is being discussed.	