

# Traumatic Brain Injury Services Coordinating Council

## Meeting Minutes

Wednesday, January 23, 2013

10:30am – 3:30pm

NYS Museum, Meeting Rooms A and B

Topic	Discussion	Action/Next Steps/Who/When
<b>Attendance</b>	<p><b>Present:</b> Michael Kaplen, Barry Dain, Colleen Scott, Michael Davison, Nina Baumbach, Lydia Kosinski, Timothy Pruce, Debbie Zetterstrom, Gerri Malone, Meredith Klein and Lisa Robateau-Epps</p> <p><b>Absent:</b> Kenneth Ingenito, Cher Montayne, Joe Vollaro</p> <p><b>Ad-hoc Members Present:</b> Ann Marie Calabrese, Jeffery Pohl</p> <p><b>DOH Staff:</b> Helen Hines, Christopher Phillips, Charlotte Mason, Michael Bauer and Cheryl Veith</p>	
<b>Welcome and Announcements</b>	<ul style="list-style-type: none"> <li>• The meeting was called to order; Michael Kaplen presided over the meeting.</li> <li>• A quorum was present and it was decided that a motion to accept minutes from the 4/20/12 and 12/10/12 meetings will be made later in the day to give members time to review.</li> <li>• Michael Kaplen introduced the day’s agenda, and announced that Judith Avner has resigned from the Council. Mr. Kaplen and the council recognized Ms. Avner’s years of service. Ms. Avner addressed the council and offered her assistance in the future.</li> <li>• Mr. Kaplen advised that pursuant to the Bylaws, he appointed Timothy Pruce as the Vice Chair of the Council and notified the council of that earlier today.</li> <li>• Mr. Pruce shared his background and experience. He thanked Ms. Avner for being a mentor to him and stated that he looks forward to serving the council in his new role.</li> </ul>	
<b>Essential Health Benefit Proposal</b>	<p><b>Michael Kaplen, Chair, TBISCC</b>  <b>Judy Avner and Erin Weaver, BIANYS</b></p> <p>Mr. Kaplen discussed stated that at the last meeting it was decided that the council would draft recommendations advising the Commissioner of the Department of Health what benefits should be included in the essential health benefits package for New York State. Mr. Kaplen has drafted recommendations based on research and suggestions made by the Consortium For Citizens With Disabilities endorsed by the Brain Injury Association of America and a proposal made by the Brain Injury Association of New York State (BIANYS).</p> <p>Ms. Avner and Ms. Weaver spoke on the specifics included in the proposal submitted to the Commissioner of Health. The philosophy behind the recommendation is that a brain injury is not a one- time injury, but a chronic condition. Ms. Weaver discussed the eight guiding principles. The recommendation requests that these be incorporated into benefits for New York’s benchmark plan.</p> <p>Mr. Kaplen presented a draft proposal which incorporates these principles and spoke on the importance of the council finalizing a proposal to submit to the Commissioner of Health. A detailed discussion between the members of the council then took place to refine the proposal. A copy of the proposal submitted to Commissioner Shah is attached.</p>	

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<p><b>State Agency Updates</b></p>	<p><b>Office of Victim Services (OVS) – Ann Marie Calabrese</b> Ms. Calabrese advised the Council that OVS has moved to the Alfred E. Smith Building at 80 South Swan Street.</p> <p><b>Commission on the Quality of Care and Advocacy for Persons with Disabilities (CQC) – Colleen Scott</b> Ms. Scott advised that CQC remains CQC and remains in Schenectady. She states that the new Justice Center will be in Delmar, and that they are still in the process of becoming part of the newly created Justice Center. The Protection and Advocacy Programs (PA) and the Client Assistance Program (CAP) are also still in the process of being redesignated by the Governor’s office. Ms. Scott states that she does not have a lot of additional information.</p> <p><b>Department of Health (DOH) – Michael Bauer</b> Mr. Bauer is from the Bureau of Occupational Health and Injury Prevention. The bureau provides data and statistics and produces brain injury prevention materials which are modeled after CDC material. Mr. Bauer advised that data and statistics and materials on sports concussion prevention, TBI prevention for parents, traffic safety, and links to other resources are available on the DOH web. The bureau is working on a PSA addressing safety of children sitting in the backseat, and has a fact sheet for policy makers. He passed out materials and advised that the materials are available on the website, and additional material may be ordered from that site. He states that he has worked closely with BIANYS to provide data and collaborate on projects through the years.</p> <p><b>Brain Injury Association of New York State (BIANYS) – Barry Dain</b> Mr. Dain advised the council that BIANYS is providing a webinar opportunity as part of the BIANYS Advocacy Series on 1/30/13 from 12:00 pm – 1:15 pm. The topic is So You Want to Be an Advocate: Federal Overview presented by Susan L. Vaughn, who consults with the Brain Injury Association of America.</p>	<p><a href="http://www.health.ny.gov/prevention/injury_prevention/tbi.htm">http://www.health.ny.gov/prevention/injury_prevention/tbi.htm</a> email: <a href="mailto:mjb13@health.state.ny.us">mjb13@health.state.ny.us</a></p>
<p><b>Protection and Advocacy for persons with Traumatic Brain Injury (PATBI) Program Services and Update</b></p>	<p><b>Christine Waters, Esq., Legal Services of Central New York</b></p> <p>Mr. Kaplen stated that he hopes that the council can make a recommendation to the Commissioner of Health (or the Governor’s Office) with regard to the redesignation of the Protection and Advocacy programs.</p> <p>Ms. Waters states that she is the designated attorney for Protection and Advocacy for individuals with TBI (PATBI). She explained that Legal Services of Central New York is a contractor with CQC since 2005 and provides the PATBI program legal advice and services to individuals with TBI statewide. With the redesignation spoken of, there will be a separation of all the Protection and Advocacy programs from a state agency—they are currently administered by CQC. The determination as to where these programs will be located has not yet been made. At this point, it looks as if this is leaning toward Disability Advocates, Inc. (DAI), an independent, private, non-profit advocacy agency. Ms. Waters states that she feels that legal Services of Central New York does do it better, though one person cannot adequately represent the entire state. Ms. Water’s agency is concerned that individuals may not</p>	

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	<p>be represented under DAI. Major concern is that there will be a Protection and Advocacy program going forward, and that it be better funded.</p> <p>Mr. Kaplen states that he will discuss further with Ms. Scott and address further at the next meeting. A discussion continued as to how address concerns that the program continue—perhaps working with BIANYS, or through copy to Governor’s office.</p>	
<b>Review of minutes 4/20/12 and 12/10/12</b>	Ms. Baumbach, OPWDD and Ms. Scott, CQC, indicated that they have minor revisions to the 12/10/12 minutes. Those were noted. Mr. Kaplen made a motion to approve with modifications. All in favor. Mr. Kaplen made a motion to approve the 4/20/12 minutes. All in favor. Minutes were accepted.	<b>Final minutes e-mailed to members 1/31/13</b>
<b>2013 Planning/Agenda Setting: Council Bylaws and Elections</b>	<p>Mr. Kaplen discussed the charge and work of the council during his tenure—successes and failures. He spoke of a TBI report done 20 years ago, and observed that the state of brain injury today seems much the same. He stated that he does not believe that this is the fault of the council. He further discussed the role of the council as well as the role of DOH.</p> <p>Mr. Kaplen stated that DOH has asked the council to look at revisions to the bylaws advanced by DOH. He stated that some of the proposed revisions make sense and some do not. He asked if there should be a committee established to work on a revision to the bylaws. There was consensus among members that they would like to work on bylaw revisions in the same way that they worked on the essential health benefit recommendations during the morning session. They felt that they successfully accomplished working together to finalize the document.</p> <p>The discussion continued among members of the council in terms of observations, accomplishments and frustrations. The consensus is that everyone is there to do good work to improve the lives of those with brain injuries. Mr. Kaplen states that he wants to put all recommendations discussed today together and share with the council in order to map the road going forward.</p>	<b>Discussion documents provided</b>
<b>Public Comment</b>	<p><b>Brent Feuz, Brain Injury Survivor</b> Mr. Feuz states that he is a brain injury survivor and a former professional firefighter. He states that he has created a protocol to identify and treat brain injury. He states that he has brought this protocol to DOH (Commissioner and Helen Hines). He states that as a paramedic there was a protocol for everything and so he developed a comprehensive protocol to help brain injured people navigate the system to get the services they need to recover. Mr. Feuz offered to present the protocol to the council and agreed to share the protocol with the council.</p> <p><b>Christine Alvarez-Ross, All Metro Health Care</b> Ms. Ross states that she is a provider of NHTD and TBI waiver services. She states that in relation to MRT the</p>	

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	<p>future of the waivers is uncertain. There used to be updates from DOH on the waivers and this would be helpful to providers. She requested that the council advocate to DOH that this information be shared.</p> <p><b>Karen Thayer, Southern Adirondack Independent Living Center</b>            Ms. Thayer stated that the council has done some remarkable work over the years and that it was the work of the council and families of the brain injured that was instrumental in the development of the TBI waiver. She states that the council has always been in an awkward position because the work of the council is broader than the work of DOH and DOH does not oversee those other services. She stated that DOH used to sponsor a Best Practices conference that was very valuable to providers, family members and survivors—perhaps the council can consider doing something similar. She stated that the council has affected change and that DOH is present and involved in the council. She encouraged the council to not underestimate the work they have done.</p> <p><b>Michael Caponero, Friend/Advocate</b>            Mr. Caponero stated that he has been attending the council meetings for seven years. And while the meetings seem full of good intentions, he has not seen anything good come from the meetings. He states that recommendations have not been followed thru, and suggests recommendations also be sent to the Senate and Assembly health committees since they oversee DOH. He stated that in order to get anything accomplished he had to take the issue to the legislature and advocate for the desired change there.</p>	
<b>Next Meeting</b>	<ul style="list-style-type: none"> <li>• The next Council meetings will be scheduled and announced. Will aim to schedule meetings in April, June and September.</li> <li>• The meeting was adjourned.</li> </ul>	