

**STATE COUNCIL FOR PERSONS WITH DISABILITIES  
BRAIN INJURY COMMITTEE  
March 5, 2018 – 2:00 PM  
Smyrna Rest Area Conference Room, Smyrna, DE**

**PRESENT:** Sharon Lyons, BIAD, Co-Chair; Andrew Burdan, Brain Injury Advocate/Brain Injury Support Group; Thomas Cairo, Bayhealth Neurosurgery; Susan Cowdery, BCBS, Highmark Health Options; Vanessa Deloach, DHSS, DDDS, Assistant Director (for Rick Komalski); Donna Dixon, Bayhealth Neurosurgery; Katie Freeman, DSCYF, DPBHS, Psychologist (for Susan Cycyk); Dr. Gerald Gallucci, DHSS, DSAMH, Program Director; Kristin Harvey, DDC (for Barbara Monaghan); Laura Howard, DHSS, DSAAPD, Deputy Director; Dale Matusevich, DOE, ECE, Education Associate, Transition Services (for Mary Ann Mieczkowski); Nancy Ranalli, Easterseals, Director of Community Outreach; Dr. Ron Sarg, DCVA/MOAA; Laura Waterland, Community Legal Aide, DLP; Zachary Cooke, Intern, SCPD and Dee Rivard, SCPD.

**PARTICIPATED BY TELECONFERENCE:** Ann Phillips, Chair, Parent of a survivor; Linda Brittingham, Christiana Care Health System (CCHS); Debbie Dunlap, Advocate, Parent of a survivor; and Jamila Waigwa, DHSS, DSAAPD (for Dava Newman);

**ABSENT:** Carol Barnett, DHSS, DSAAPD, Planner II; Kathlene Brittingham, DHSS, DSAMH, Executive Secretary; Sybil Brown (for Wendy Strauss), GACEC; Kathie Cherry, Governor's Advisory Council for Exceptional Citizens (GACEC); Tammy Clifton, DOL, DVR, VR Counselor I; Felicia Connor, Jane Crowley, Dawn Edwards, DHSS, DSAAPD, Sr. Social Worker/Case Manager; Fran Haggerty, Michelle Hood, St. Francis LIFE; DOE; Jody Hougentogler, BIAD; Mary Iampietro; Nicol Joseph; Larence Kirby, DOS, Commission of Veterans Affairs, Executive Director; Chris Malaney, Cynthia Mercer, DHSS, DSAAPD, Planning Supervisor; Maria Miller; Jennifer Oppel, Melissa A. Smith, DHSS, DSAAPD, Planner; Tiffany Stewart, DOE, Brandywine School District; Clarence Watson, DHSS, Medical Director; Leah Woodall, DHSS, MCH Deputy Director;

**GUESTS:** Marika Ginsburg-Block, University of Delaware;

**CALL TO ORDER**

Co-Chair Sharon Lyons called the meeting to order at 2:05 p.m.

**ADDITIONS/DELETIONS TO THE AGENDA**

None

**APPROVAL OF PREVIOUS MEETING'S MINUTES**

Katie Freeman motioned to approve the February minutes as prepared, with Vanessa seconding the motion; Co-Chair Sharon Lyons asked if there was any discussion, additions, changes, or deletions to the February minutes. Katie Freeman asked to correct the word "TBI's" to "children with acquired brain injuries" in the second paragraph under DOE – Eligibility for TBI (Dale Matusevich) portion of the minutes. The Co-Chair called for a vote on the motion to approve the

February 5, 2018 minutes as amended. Committee members in attendance unanimously voted to approve February's minutes as amended by Katie.

## **OLD BUSINESS**

### Traumatic Brain Injury Eligibility Presentation & Discussion

- Dale Matusевич began the discussion by stating that this topic was discussed at the end of last month's meeting. Dale advised that he is working with Marika Ginsburg-Block from the University of Delaware/DOE for 925 who is facilitating the groups for us. Marika was able to join us today and will review the PowerPoint presentation. Dale provided handouts from the last meeting for those in attendance that included a sheet containing the IDEA Federal definition, the Delaware Traumatic Brain Injury definition and Stakeholder recommendations from the last meeting, a table containing other state regulations on TBI for comparison, a one page handout from the American Psychiatric Association on Mild Neurocognitive Disorder and an updated PowerPoint Slide printout. Dale stated that he may have one more meeting with this group before he and Marika go back to the DOE for their recommendations to go out for a 60-day comment period. Ann asked if we could put his document on the website to take comments as well; however, Dale felt that the best way to share it is for him to provide a link to where it is posted so everything will be together in one location.
- Marika said that it sounded like the last time Dale met with our committee he got the conversation started. The PowerPoint presentation is basically just a recap from the first meeting and has to do with some of the challenges that the IT group is having when working with the TBI eligibility criteria discussion.
- One challenge raised by participants was that some children might be served under a 504 plan and others under an IEP. Handout for IDEA federal definition, Delaware TBI definition and Stakeholder Recommendations from meeting 1.
- Marika reviewed the handout "TBI - other state regulations for comparisons" asking everyone to look at Wisconsin's Administrative Code. When you look at Delaware's criteria there is only 3 parts to it.
  - The first part deals with the criteria in order to be considered for special education and related services.

- The second part deals with if the TBI substantially limits one or more major activities of daily living.
- The third part deals with the child's age.
- One possibility is to adopt the federal definition and the second is that if it is not broke don't fix it. All recommendations will be shared with DOE. The big ideas are up for discussion.
- Sharon Lyons felt that the word concussion minimizes the definition because some people are not very symptomatic while others are very, very symptomatic. There has to be better education out there because some educators have actually told parents that concussions only last for a couple of weeks. These children need support, the same kind as children who were hospitalized for 3 months.
- Katie Freeman said that most children are getting served under 504 plans. However, there is a select group of children that need this help long term. How do we best serve those who need long-term support and accommodations as opposed to modifications?
- Anne Phillips stated that the federal definition does not state how long the symptoms last and Kristin Cosden stated that our TBI clearly defines activities of daily living as well as specifying a period of time.
- Katie mentioned adaptive functioning with some of the children not looking that impaired. However, when looking at the child's executive skills they are really hit hard along with the language skills. She believes that we should keep in that they should have a daily functioning deficit like the GAC on the adaptive skills set; however, the executive skills set is a mess. As a teen they do not have to navigate the community or call a repair man so they do better.
- Kristin advised that the DD Act's guiding legislation could possibly be modeled for children from birth to age 9; however it is likely that it will be needed in the future.
- Laura Waterland and Marika spoke about Delaware's definition being narrower. Definitions should be as clear as possible so we know what we are going to follow. Someone asked if it would help to add more descriptors. It was suggested that we should add a little bit more emphasis on the descriptors.

- Sharon Lyons added that people tend to forget about children that were abused. She asked if anyone ever asked parents if their children were hit in the head because that could possibly be the cause of the child's behavioral changes.
- Marika stated that right now there is no mention of concussion and that is something that we might want to clarify having to do with the concern of children that have other brain injuries like anoxia and stroke. The federal definition is kind of limiting and it is interesting because in looking at another state, Wisconsin names acquired injuries to the brain that are included. Given our current regulations now you might find children being served under different areas because of our definitions.
- Katie finds that a lot of the children that present with acquired brain injuries mimic other health impairments. Teachers tend to minimize everything when other health impairments are listed because in the real world it doesn't carry the same weight and does not help the child as much.
- Anne Phillips talked about Dr. Crowley's PowerPoint presentation.
- Kristin likes Wisconsin's TBI definition and thinks that Delaware should model our definition after Wisconsin.
- Sharon talked about children going through elementary school just fine; however, when they get to middle school they have trouble.
- Tom Cairo from the Bayhealth stated that Michigan's definition is similar. While you may not be required now to meet the definition but you will later.
- Susan Cowdery spoke about the untoward effects after every injury.
- Anne believes that it helps to widen the TBI definition and also to assess at the time of injury in elementary school vs. waiting until they are in middle school. A brain injury can be so many other things that we should follow through with this definition.
- Marika stated that it sounds like the committee's major suggestions are to move away from any suggestion that talks about daily living skills and to talk about broadening our definition to include strokes, anoxia and other examples.
- The third topic dealt with the assessment section. Many of the categories of the 925 Children with Disabilities regulations deal with evaluations and eligibility.

- In response to Marika inquiring whether anyone had opposing suggestions, Sharon Lyons asked whether or not there are some really good assessment tools. Katie stated that the problem is that a lot of the schools are not trained to utilize the assessment tools. A suggestion was made that perhaps the school could provide an independent psychological assessment. Marika shared that Orthopedic and OSI require an assessment. No child in Delaware should lack access to having that. However, schools don't want to be the only medical professional treating a child. Katie stated that a neuro-psychological examination is very helpful for everyone involved in the child's treatment. Marika shared that right now Delaware's definition states that a qualified medical professional should state that the individual has a brain injury. She acknowledged the difficulty in obtaining a note from the doctor stating that an individual has a TBI.
- Katie spoke about terminology while Susan Cowdrey shared information on health care providers. Nancy Ranalli mentioned that children have to pass something if they are diagnosed with a concussion in order to return to sports; however, there is no evaluation to assess where they stand for attending/returning to school. Ann Phillips shared that Pennsylvania has something called BrainSTEPS. The BrainSTEPS Program was created to build a bridge connecting the medical, rehabilitation, education sectors and families following student (K-12) acquired brain injury (ABI). Sharon shared additional details stating that if a child has a brain injury, someone from BrainSTEPS will go and talk to the school personnel to explain how someone with a brain injury is different and how they need to be treated. BrainSTEPS consulting teams support school teams in the development and implementation of educational plans following student ABI. Brenda Egan Brown started BrainSTEPS in Pennsylvania and is their program coordinator. BrainSTEPS was recognized by the Centers for Disease Control (CDC) as a national model for educational consultation supporting students and school teams in the development and implementation of educational supports and services following an acquired brain injury. She spoke at one of BIADs conferences and she was very informative. Brenda's email is [eaganbrown@biapa.org](mailto:eaganbrown@biapa.org) and her phone number is 724-944-6542.
- Marika shared how DOE plans these stakeholder meetings mentioning that they have 3 groups. During the last meeting New York, North Carolina, and Ohio were mentioned as the three states that we wanted to look; however, none of those states were included in the

TBI – other state regulations for comparison table. Marika asked if there were other documents that the group should look at. It was suggested that committee members could look at the language the Committee wants to adopt and review it during another meeting. With no other questions or suggestions, Dale requested that we add him to the April agenda in order to finalize recommendations for him to take back. Dale mentioned that he is also having conversations with Mary Anne. Most groups are going to finish up their review and recommendations during late March into early April. The Brain Injury Committee's next meeting is April 2.

#### Follow-Up- DHIN (Delaware Healthy Information Network)

- Thomas Cairo stated that there was no diagnosis list brought to the meeting and no one present to discuss DHIN follow-up during this meeting. He stated that the next thing the committee needs to do before going to DHIN is for committee members to email him a list of things that we want to include for him to compile and bring to our April meeting.
- Sharon summarized that Thomas wants separate diagnosis or ideas of what this committee would like to have included. Sharon shared that she takes a lot of phone calls and can look back through her notes to pick out specific diagnosis codes. DHIN wants to use the codes to understand the number of people who could benefit from our aid and get the information out to the people so they can know what information is out there and what resources they have available to them. Sharon asked Thomas if he wants to have the different types of brain tumors and questioned what kind the committee wants included in our data request.
- Nancy added that this dovetails with our previous discussion and that we could use some of the handouts and some of the information from other states. We could also look at documentation from trust requests.
- Anne shared that with the current opioid crisis there are a lot of people who overdose, survive, and now have brain injuries. If that is a new unfortunate trend it is something that we should look into as well.
- Thomas is working with the state, specific to Bayhealth with PDM and what they are doing at the local level to ensure that patients are receiving the treatments they need. It will be interesting to see if we could include that from the DHIN level.

- Nancy thought that we would be looking at how many cases we are seeing and what the real numbers are that we are seeing.
- Dr. Jeremy Gallucci mentioned that perhaps we could use Medicaid data because it has good information on how much services are used by people with brain injuries. He is not sure if any work has been done with the Medicaid data and brain injuries as to specific diagnosis, service utilization, and how much money is being spent or not being spent. Kristin Harvey inquired how the average person would access that data. Dr. Gallucci stated that the University of Delaware has an agreement with Medicaid to look at that information. An interested user just has to fill out a one page report and send it to Steve Groff to request what data they want to look at and include the reason they are looking at the information.
- Thomas Cairo understands that from the last meeting Anne was inquiring if anyone was interested in taking more of a lead role because she was looking for some of those people who might be interested. Please let Anne know if you are interested in taking more of a lead role on this topic.
- Please send your emails with your suggested list of data and/or diagnosis codes that you think the committee should include in their data request from DHIN. His email address is: [Thomas\\_Cairo@bayhealth.org](mailto:Thomas_Cairo@bayhealth.org)

#### Legislative Priorities

- Kristin Harvey told everyone that DDC worked with numerous groups to create legislative priorities listing the top 10 legislative priorities. She previously sent the list to Jo mentioning that Jo shared it with all of the BIC members. If anyone has any questions please contact anyone from the DDC staff.

#### Strategic Plan Priorities

- Ann couldn't find this information in the last meeting minutes at first. However, she stated that it is written under the Needs Assessment section. Part of the reason for the Needs Assessment was to blend in what was needed for the strategic plan.
- Sharon Lyons stated that the committee is looking for a list of recommendations to develop by TBI, the established database for eligibility, establish a continuous funding stream, etc. (see page 3 of February's meeting minutes). This is when we looked at it and decided that

a TBI Registry was the most important. Recommendations from last month's meeting were to:

- Develop one common TBI registry that is used by all agencies and hospitals to collect prevalence and incidence data for TBI.
  - Correct outpatient discharge data for patients with mild TBI.
  - Establish a database of TBI-specific services and eligibility requirements of existing services.
  - Establish continuous funding streams to support brain injury treatment and rehabilitation.
  - Establish and fund an in-patient/out-patient rehabilitation facility specific to the needs of TBI.
  - Establish and fund adult day programs specific to the needs of individuals with TBI.
  - Provide additional funding to state agencies serving individuals with TBI.
  - Improve collaboration between service provider agencies.
  - Provide additional trainings and educational opportunities for staff. The Brain Injury Association tried that recommendation at the Brain Injury Conference, but it was not successful.
  - Investigate other states' registries and service delivery models for individuals with TBI. This recommendation is always changing. New Jersey provided the best model and different administration came in and the funding went away. This is the most difficult one to keep up. Ann suggested that the Committee could still look at models that were used.
  - Explore and implement TBI prevention programs that reach individuals of all age groups, ethnicities, and in all counties.
  - Implement a screening tool for children outside of the special education system who may have sustained a TBI.
- Anne advised that she thought that we made the provider network the most important. Anne stated that we definitely talked about the registry and that it may be priority number 2. Priority 2 goal 2 is to "Improve state data collection system on individuals with brain injuries, their needs, and the services." We cannot have one without the other. No one from Public Health attended today's meeting and Anne knows that John sent a letter requesting representation. Clarification from last month's minutes showed that the first goal under the first priority was to facilitate the ready availability of information on resources and services useful to persons with brain injury and their families.

- Dr. Gallucci asked if the goals are set or if there is room to change some of the goals. One of the objectives that could be included under this data piece is a group in Philadelphia that works with public health management that has previously worked with the State of Delaware. He told the committee that they could add questions to the existing survey. He is unsure if any of the current questions relate to TBI. You can add questions for a nominal fee of \$3,000 per question to ask respondents: Have you ever had a brain injury? Have you ever received treatment for a brain injury? The population set is specific to Delaware. He advised that although the committee would have to pay to add the questions that it might be a good opportunity for this group. There is also a CDC Health Survey, if there is no population data on brain injuries available that is also available. The Division of Public Health was involved with the initial survey on behavioral risk survey.

#### Social Media Options

- Sharon advised everyone that Thomas was handling the social media option and since he left, members will wait to discuss the Social Media options at the next meeting.

#### **NEW BUSINESS**

##### Other funding opportunities for the Brain Injury Committee

- Sharon and Anne asked everyone to keep their eyes out for possible funding opportunities for BIC.

##### Two funding opportunities for Traumatic Brain Injury State Partnership Program.

- Information on other funding opportunities for the BIC was shared with members in the email with this meeting's agenda. The opportunity involves a state implementation grant and a state mentor grant. The state implementation grant would be the grant to go after, however that is why we need DSSAPD and Public Health's participation to determine their willingness. However we again have this viscous circle that we cannot get the grant without the data and we do not have the data. We need someone to take the lead and say that they are willing to work on this. We need to speak with Public Health to see if they are willing to take the lead. After this meeting Anne agreed to talk with John to see about setting up an in-person meeting. This grant is only offered every three years or five years. We need

the support and match from the state. Anne will follow-up after this meeting. Katie stated that we need the grant in order to get the information.

- Anne added that our neighboring state who gets the grant for mentors will also help us and be an asset with strategy for us. However, we have to have the first step or two. We can say that we don't have the registry and that will be our first step.
- Kristin stated that there are potential resources out there but just being able to quantify what we are asking for and getting the diagnostic codes is important. Anne stated that the very first thing is getting the state on board.
- Dr. Gallucci advised that DSAAPD would be the more appropriate section of Public Health.
- Anne shared that the last time we tried that she called the National Brain Injury Association and when she contacted them they both thought that it was Public Health. She could be remembering incorrectly but she believes that this is an accurate statement of what she remembers. Anne does not know how easy it is to change agencies; however, the last time around they made it sound like it is not an easy thing to do. Sharon shared that before it was when our grant expired and we were trying to get it again that Public Health said it wasn't them.
- Laura Howard from DSAAPD requested that someone send her the information on the grant opportunity for her to take back to DSAAPD and the Division of Public Health. She said that she would be happy to take a look at the information and perhaps talk it through with our partners in Public Health in order to look at the opportunity to see what might be best. Dr. Gallucci added that perhaps DSAMH might also be interested.

#### Needs Assessment (done in 2007)

- Anne Phillips advised that at the last meeting that Thomas suggested and everyone agreed with contacting the agencies or groups that had previously responded to the survey from 2007 to use that as a starting point. She stated that we previously agreed on having to determine: What kind of information we need to get back from them? What information is missing? What do we have to do to work on the goals?
- Katie advised that we were also talking about using the survey for some of the questions of what we need to ask DHIN. Doing two assessments at the same time is probably not a

good idea right now and she suggested that we use the survey as qualitative information. Ultimately this would let the committee use the Needs Assessment to garner questions for DHIN.

- Anne requested that members of the committee that work for any of the agencies that previously responded to see if they can find out if their agency is listed as participating on the survey and can answer affirmatively. She asked all of the members to review the survey for the next meeting as to whatever they can find out about the survey.
- Kristin advised that there is a table on page 8 of the survey listing the agencies contacted that included DOE, DDDS, DSAAPD, and DSAMH who are all represented on the BIC. Kristin verified that Anne is asking the representatives here today to take the survey back to their superiors to discover what information reported in the survey is the same or different. The survey is found at the back of the Needs Assessment.
- Nancy Ranalli suggested that essentially the agencies could take the same surveys again. The results of the survey would be used to determine what information we want from DHIN.
  - Sharon suggested just asking the agencies informally if they have services and if they know how many people they are serving.
  - Katie advised that some of the survey questions need updating before we ask them to take a formal survey again. We don't want to overlap data sources. DHIN is clinical information and at the diagnosis aggregate level where this survey is more qualitative. Services provided by the state are in a different category than what we would get from DHIN. There is minimal overlap.
  - Nancy suggested having them retake the same survey to see if the gaps are the same or what has changed in the past almost 11 years. Has anything changed? Or is what the SCPD and the Brain Injury Committee have done great because there is a significant amount of additional services?
  - Laura Howard from DSAAPD felt that the questions are fairly general and should not be a problem for agencies to respond to.

### Membership Vacancies

- Anne spoke about membership vacancies and noted that Jody Hougentogler is not in attendance today.
  - Sharon stated that she can share information on the Brain Injury Conference.
  - Anne advised members that based on what was written into the legislation for the Brain Injury Committee (see attached) we want to ensure that we have representation from each agency at every meeting in order to be more productive and effective.
  - Sharon felt that it is also important to have representation from hospitals other than Bayhealth.
  - Anne advised that the committee needs to know who we are required to have and then fill in members accordingly. We want to fulfill our legal obligation and then ask people who serve persons with brain injuries about becoming members.

#### **ANNOUNCEMENTS**

- Sharon Lyons reminded everyone about the 27<sup>th</sup> Annual Brain Injury Conference scheduled for March 15, 2018 at the Dover Downs Conference Center. In response to a question from Anne Phillips inquiring if it was true that this year's conference was focusing on alternative therapy Sharon read everyone the conference agenda. Sharon asked Anne and the other members if they had received emails about the conference to which the majority of the members responded that they had not received email communications about the conference.
- Anne stated that she is not comfortable promoting something that is not covered by insurance. Sharon shared that she also shares Anne's dilemma in addition to having angst about the neurotherapy. However, this conference is all about alternative modality. Anne stated that this is exactly why she is not registering Aaron because she knows that he will get excited about something that is not affordable and is not covered by insurance.
- Sharon told members that the 27<sup>th</sup> Annual Brain Injury Conference is scheduled for next Thursday with the first topic called "Embracing the Journey" with Amy Zellmer. Amy will speak about her personal journey through traumatic brain injury. Her speech is followed by the first set of breakout sessions where attendees can choose between sessions on "Emerging Alternatives", "Veterans & Community Resource," or "Mindful Meditation."

The second set of breakout sessions offers attendees a choice to attend sessions on “Nutrition and the Brain”, “Lifespan Waiver and Pathways to Employment,” or “Medical Cannabis.” Following lunch, Joel Goldstein the keynote speaker is presenting on “The Conspiracy of Decency: Cross Disciplinary Advocacy for People with ABI and Their Families” and is accompanied by survivor Bart Goldstein. Keynote speaker Joel Goldstein will speak about alternative therapies that helped Bart. Following Joel Goldstein’s keynote address attendees can choose between sessions on “Mitochondria and Neurologic Injury,” from presenter Dr. Lewis Clark who specializes in chiropractic, brain based therapy; “Staying Connected with Danio Diary,” a healthcare social app that provides family members real-time updates from care providers; and “Neurotherapy: Treatment Options after TBI” by presenter Lauren Haggerty and Christine Holfelder talking about cranial massage.

- Nancy Ranalli asked Sharon if Medicaid or anyone from Medicaid is planning to attend this conference to learn more about these alternative services, to which Sharon responded no, to the best of her knowledge.
- Kristin Harvey asked if there could be a plant in the audience to raise the question as to whether or not these services are covered by Medicaid.
- Sharon reminded everyone that the TBI Fund voted to cover only an initial 10 sessions of neurofeedback therapy and no more.
- Katie Freeman told everyone that insurance companies are having enough trouble covering evidence based treatments.
- Anne Phillip reminded everyone that insurance companies will not cover experimental services.
- Nancy Ranalli stated that it happens with everything; however, you have to let people know what treatment options are out there.
- Katie advised letting people know that the services are not covered by insurance companies as you tell them about the services.
- Andrew Burdan said that getting them excited about alternative treatments is going to turn them into your best advocates. We have to keep in contact with them because they will advocate for the brain injury services. You can’t be scared about telling them about

alternative therapies just because insurance companies do not currently cover the therapy.

- Vanessa DeLoach stated that people will pay for what they want and beg for what they need.
- Anne stated that today we have social media and it is much easier for people to go online and ask others what they have seen and if they have tried a particular treatment. People will share how long it has been around and whether or not the treatment has shown any benefit. People need to find out if there are clinical trials that they can be part of for alternative treatments.
- Sharon shared information on a previous client who they tried enrolling in a clinical trial and how well she responded. Sharon said that she ended up having a pretty good life after the clinical trial.
- Nancy stated that some things work for some people and not for others. People don't know that a particular therapy or treatment is out there if they are not told about the alternative therapies. She felt that it is important for clients to have questions to ask so they can feel better about what they are doing and have something to tell their insurance company. Nancy felt that Lauren Haggerty's talk could be a little self-serving because she is doing a talk on a therapy that she is the only provider for in Delaware.

## **ADJOURNMENT**

With no further business the meeting adjourned at 3:45 p.m.