



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES

Margaret M. O'Neill Bldg., Suite 1, Room 311
410 Federal Street
Dover, Delaware 19901
302-739-3621

The Honorable John Carney
Governor

John McNeal
SCPD Director

BRAIN INJURY COMMITTEE MINUTES

August 5, 2019 – 2:00 PM

Smyrna Rest Area Conference Room, Smyrna, DE

17 in attendance of 24 **QUORUM PRESENT.**

PRESENT:

Tammy Clifton, DOL/DVR, Senior Vocational Rehabilitation Counselor and **BIC Chair** (obo Andrea Guest, Director); Christine Applegate, Nurse Navigator, Neurosurgery, Bayhealth Neurosciences; Nidhi Atri, Psychiatric Resident II, DHSS/DPC/DSAMH (obo Elizabeth Romero); Sybil Baker, GACEC (obo Wendy Strauss); Linda Brittingham, Christiana Care Health System (CCHS); Sue Campbell, Birth To Three (obo Sue Gamel-McCormick); Nicholas A. Duko, Program Mgr., BCBS Highmark Health Options; Katie Freeman, Psychologist, DSCYF/DPBHS, (obo Robert Dunleavy LCSW); Kristin Harvey, DDC (obo Rick Kosmalski); Jeffrey S. Hysan, Paralegal, Community Legal Aid Society, Inc., Disabilities Law Program; Miguel Marcos, TCM Program Manager, Wilmington VA Medical Center; Dale Matusevich, DOE, ECE, Education Associate, Transition Services (obo Mary Ann Mieczkowski); Karen McGloughlin, Director of Women's Health (obo Dr. Karyl Rattay, Director); Dr. Ron Sarg, DCVA/MOAA; Carey Swartzentruber, Survivor; Jamila Waigwa, DHSS/DSAAPD; and Megan Witman, Director of Therapy Operations, Encompass Health;

ABSENT:

Andrew Burdan, Brain Injury Advocate/Former Support Group; Thomas Cairo, Bayhealth Neurosurgery (Designee obo Christine Applegate); Sue Gamel-McCormick, APRN, DHSS/DMS/Birth To Three; Sharon Lyons, President of BIAD and **BIC Vice-Chair**; Christina Miller, Insurance Investigator Supervisor, Department of Insurance/TBI Survivor; Ann Phillips, Parent of a survivor; Dorothy Prior, Psychologist, (obo Marie Nonnemacher) (DDDS); Nancy Ranalli, Director of Community Outreach, Easterseals; Tiffany Taylor, Nurse Navigator (obo George DelFarno, Director, Post-Acute Medical Rehabilitation (Dover);

ADDITIONAL ATTENDEES: (Not able to vote or count toward quorum)

IN-PERSON – John McNeal, Director SCPD and Survivor; Dee Rivard, SCPD

TELECONFERENCE PARTICIPANTS: N/A

CALL TO ORDER

Tammy Clifton called the meeting to order at 2:05 p.m., after all members completed signing-in.

- Tammy thanked everyone for attending requesting everyone to introduce themselves for the benefit of anyone new.

ADDITIONS/DELETIONS TO THE AGENDA

Tammy inquired if there were any additions or deletions to the agenda. Hearing none, Kristin motioned to approve, Ron Sarg seconded and voting committee members in attendance unanimously approved the agenda as prepared.

APPROVAL OF PREVIOUS MEETING'S MINUTES

Tammy inquired if everyone had sufficient time to review the minutes of our last meeting on July 1 and inquired whether members had any additions, deletions, or corrections to the minutes.

- Ron requested a correction to a typo on page 7 to change the word "date" to the word "data" so the sentence correctly reads: "The DHIN is starting to obtain agreements to receive data from the independent "Doc in the Box" locations."
- Ron also suggested a grammatical correction on page 9, half-way down the page to correct the word "her" to the word "she" so that the sentence correctly reads: "John offered 'Kudos' to Karen for everything that she and her subcommittee members' accomplished so far."
- Ron suggested a correction to the phrase "back Delaware" to improve the readability of a sentence on page 11 by inserting the missing word "to." The sentence now correctly reads: "Six Delawareans are currently being housed out of state at an exorbitant cost to the state; however, one member heard that someone is working to bring the six back to Delaware as soon as they can find a place for them."
- Tammy requested a correction on page 9 to add the third bulleted sentence with the second to create one paragraph for accuracy. The sentence "John stated that if there are federal funds that we are looking for that are available, the SCPD/BIC will

now have a tool to use for justifying their request" is now a part of the second bulleted item.

- Ron Sarg made a motion to approve the minutes of the 07/01/19 BIC meeting as amended, that Karen McGloughlin seconded and voting committee members in attendance unanimously approved.

SURVIVOR INPUT

Carey shared that he currently has people working with him to obtain a psychiatric evaluation on the 17th in order to see if he has any autism contributing to his issues. Carey shared that his memory is still really difficult, which is causing him a great deal of frustration. Carey shared that he spoke with his grandfather to find out if his grandfather's forgetfulness caused him any frustration. However, Carey's Grandfather stated that he doesn't experience any frustration due to his forgetfulness. Carey feels that his progression is an issue because his memory feels like it falls off a certain times which ends up leaving him not knowing things like what happened, things that people told him, etc. Carey visited with the Department of Insurance (DOI) and they are following up for him relating to a legal document to see what could happen. Carey also shared that he has a question on the payment of equipment and services in advance. Carey shared that he had a valid prescription for a Hyperbaric Chamber from his physician that he paid for in order to obtain; however, no one is willing to reimburse him even a portion of the purchase price of this very expensive, prescribed equipment. He suggested that moving forward this committee might consider providing education and awareness to survivors to make them aware that the approval process is long and contains many steps. Also that everyone requires obtaining approval for equipment and services recommended by physicians in advance. Carey still has difficulty with the wording of documents and understanding their content. Survivors really need someone to help them navigate the process.

OLD BUSINESS

- Data Development Subcommittee Survey Completion
 1. Karen told everyone that the electronic copy of the survey they all received prior to today's meeting is in sections so that if an agency does not do research or they are not going to apply for funding members can simply enter N/A for that area. Please return all surveys to Dee before the September 9 meeting.

- Motorcycle Helmet Advocacy
 1. John told everyone that the SCPD is working in the next couple of weeks and months toward preparing the 2020 Legislative Priorities Report for all of the disability councils. Typically these ideas come from the full council; however, this year each council will submit 3 suggestions for inclusion in next year's legislative priorities.
 - The Helmet Bill hasn't been addressed in approximately 3 years so this is an opportunity to reach back out to everyone on this initiative. Every other day someone is killed or injured in Delaware and it doesn't just affect that individual, it affects their entire family and community.
 - John advised that Delaware has a small group of individuals who have been very persuasive with the Legislators in the past. This year there was a great transformation in the Delaware General Assembly with the influx of new legislators.
 - The Helmet bill is a crucial piece of legislation that we need to bring before the legislators. Did you know that from New York to North Carolina there is only 60 miles of roadway where a motorcyclist can take off their helmets and still legally ride on the road? This is because all of the other states already passed helmet laws. Hopefully this will be a legislative priority coming out of the Brain Injury Committee.
 - Karen asked how the Data Development Subcommittee could help and what kind of data should the subcommittee request.
 - John stated that he will put together what he needs in order to support the 2020 Legislative Priorities and passage of a helmet bill to send to Karen for her Delaware Health Information Network (DHIN) data request.
 - John advised that as part of the Department of Safety & Homeland Security (DSHS) this committee needs to reach out to request information from the Office of Highway Safety (OHS), Delaware State Police (DSP), and the Department of Transportation (DelDOT) because they can assist in putting a cost figure to the data request as well. The cost is in the hundreds of thousands of dollars and the cost for traumatic brain injuries is in the millions of dollars. The value however, is in the saving of lives and the improvement and sustenance of their quality of life.
 2. Ron Sarg was present for the Helmet bill committee 2 years ago sharing that there was every conceivable piece of data available and then there was Abate. At the meeting, several of them related their personal encounters stating that nothing was wrong with them. It was more of an emotional mine field rather than about what the cost to the state and healthcare was. The main message was "Don't take away my rights" and the committee just fell in

line. However, the bottom line is that other survivors were in favor of passage of the bill. Medical experts from Johns Hopkins Hospital and other medical institutions out-of-state attended and presented very compelling data; however, because it was an emotional battle not a fiscal one the emotions won. Karen agrees with John that we need to keep pressing for passage of this bill. Ron stated that it is very important to know the Chair and committee members and their preferred method of appeal. John felt that there are a number of things that this Committee can do especially with a turnover of 23 legislators. SCPD and the BIC need to do a lot of work one on one prior to the bill's committee hearing. Tammy stated that we take very seriously the rights that were given to the people in this country; however, we also take very seriously the rights of individuals following a traumatic injury. Karen stated that the Prevention & Outreach Subcommittee and the Data Development Subcommittee could work together to create a new fact sheet to put in front of the new legislators. John shared that he will reach out to Representative Sean Lynn. If this bill ever gets out of committee there will be a plethora of motorcycles parked outside of Legislative Hall. For every motorcycle rider without a helmet there are probably 50 or 60 who ride very responsibly. The Brain Injury Committee needs to get them to speak up for the young riders that follow them in order to have them be advocates for those coming after them. John stated that he will need to get a copy of the legislation for Dee to send out in an email for everyone to review in order to make recommendations. This is a really good legislative piece if the Brain Injury Committee wants to move forward with it like similar legislation in the past including the bicycle helmet bill and the Concussion Protection in Youth Athletic Activities Act (CPYAAA). Following this piece of legislation, it is recommended to target seat belts in school buses.

- Christine Applegate made a motion that the Brain injury Committee would work toward getting a motorcycle helmet law passed in Delaware that Ron Sarg seconded and voting committee members present unanimously approved.
- School Nurse Training on Concussions and Brain Injuries.
 1. Karen requested to postpone her presentation on this topic until next month since she has not had the opportunity to look into it. Dee will send her a reminder prior to the next meeting. [September Agenda Item.]
 2. Dale Matusevich stated that he previously linked someone from the BIC with the individual who is over school nurses in the spring. Dale will send Karen the head of the school nurses for the Department of Education (DOE) since Linda retired. Katie inquired if this is part of the Prevention & Outreach Subcommittee. Karen responded that it was just a general discussion on the floor with concern over the appearance of lack of training for after school

activities and non-school affiliated groups using school grounds. The Prevention & Outreach Subcommittee is working on creating an informational packet. Are we looking into developing a guide or looking into requiring training? Karen stated that she is just looking into what we have now. The Prevention & Outreach is looking into information on concussions and traumatic brain injuries (TBIs) to share with school nurses. The Centers for Disease Control & Prevention's (CDC) Heads-Up Committee has information specific information for schools and school personnel on their website. John volunteered to help by looking into this as well. The Prevention & Outreach Subcommittee should look at the same pages in order to provide Delaware specific rules, guidelines, etc., because the CDC is at the national level.

COMMITTEE & SUBCOMMITTEE UPDATES

• TBI Fund Application Review Committee Update

- Katie Freeman, Co-Chair of the TBI Fund announced that this committee met immediately prior to the Brain Injury Committee meeting today.
- The TBI Fund Committee has definitely seen an increase in application submissions; however, we would love to see even more applications submitted.
- Committee members approved driver training for one of our applicants who already received specialized driving equipment and an assessment through Moss Rehab all of which were paid for by the TBI Fund.
- So far this year, the TBI Fund received 18 inquiries with 6 applications fully funded and closed. Committee members are keeping the process moving forward on application reviews and approvals or denials.
- Earlier today, committee members approved home modifications for a first floor accessible bathroom for another client.
- Committee members love hearing the feedback from approved recipients and their families who are thrilled with their funded items. Katie provided several recent examples for committee members.
- John McNeal advised that if this subcommittee approaches the end of the fiscal year and there is something that is above the standard that the committee needs to spend the money for the benefit of survivors. John stated that the TBI Fund Committee is doing a great job helping survivors. John wants to expand the definition of TBI. John shared that our HMOs under Medicaid also provide funding for home modifications. Karen wanted to know if perhaps the two could work together if the cost were exorbitant for the fund to split the cost of the modifications between the HMOs and the TBI Fund. There may be a need to sign an MOU or MOA with Medicaid after completing an in-home assessment. Let's have an MOU in place so if there

- are any cases where the HMO will only pay a certain amount that we are already in a position to have cost-sharing for the benefit of the survivors.
- Nick shared that a Medicaid recipient with a managed care organization must also be in the LTSS Program to receive this benefit and the amount is limited to \$6,000 per project, \$10,000 per year, and \$20,000 for a lifetime. He shared that they have had patients who were members that tried to piece-meal payment; however, they wanted Highmark to cut them a check. He advised that they have trouble getting reliable providers who don't over charge. The health insurance companies do look for other funding sources as well as looking at medical necessity. They also look at what is the definition of the benefit and ensure that it is a MINOR modification not a home renovation. Dee will share the TBI Fund vendor list with Nick.

- **Data Development Subcommittee (DDS) Update**

- Karen McGloughlin shared that the DDS is requesting responses to the survey that Dee sent out prior to the next BIC meeting.
- The DDS members are moving forward from their huge success of last meeting. Members met as a data subcommittee and decided that when the Delaware Health Information Network (DHIN) Requests are made the DDS members will manage the requests.
- Christine Applegate volunteered to head up that portion of it with her working group also laying out the parameters of what is required from someone requesting data. If you are interested in working more closely on this please let Dee know that you want to work with Christine and her Data Working Group.
- John shared that he will reach out to DHIN CEO Randy Farmer to work on getting the required Interagency Data Agreement signed prior to the next meeting.

- **Prevention and Outreach Subcommittee Development**

- Christine Applegate, Chair announced that the Prevention and Outreach Subcommittee met last week to focus their direction on where they want to go and how they are going to proceed.
- This subcommittee is working on gathering information together in order to possibly send letters to hospital managers, case managers, social workers, etc.
- Subcommittee members are also working to develop uniform presentation speaking points and to decide which materials they want to include on the SCPD website and what information to include as part of their outreach.

NEW BUSINESS

- Retreat -- John announced that while this summer was very busy; he is still planning on scheduling a retreat for the Brain Injury Committee members. The first priority is coordinating schedules with Rita Landgraf to act as retreat facilitator and to find an accessible location. John will work on scheduling it as soon as possible so as not to conflict with the SCPD Annual Luncheon that is always held in October.
- Karen McGloughlin shared that she recently attended a strategic planning meeting with leading government officials who decided to use a nifty tool to help with the strategic planning. Karen promised to share the tool with Dee that the Division of Public Administration developed. She felt that this tool was a nifty way to walk someone through strategic planning including brainstorming, determining difficult vs. easy tasks, and high-impact vs. low-impact tasks. She advised that the tool is only 10 pages long with graphics and that it is definitely worth everyone reviewing.

ANNOUNCEMENTS

- John shared a couple of announcements:
 1. Some of you may know that the dental access for Medicaid recipients passed both chambers with the bill signing scheduled for tomorrow in Wilmington. The State Council for Persons with Disabilities (SCPD) worked on this type of bill for at least the past 25 years.
 2. John and Kyle recently attended a Town Hall meeting with Secretary Walker from the Delaware Department of Health and Social Services facilitated by Rita Landgraf. During the Town Hall they announced a recommendation for The Governor's Commission for Access to Community Based Services to merge with the SCPD. This merger provides an opportunity for more people with disabilities to join the SCPD and will require the presence of cabinet secretaries and directors as participants at the table. John advised that the SCPD has an opportunity to make some real changes and differences. Legislation is being devised for us to move forward on this initiative. The Cabinet Secretary and Rita Landgraf both support hiring additional staff to work with Kyle Hodges on this. It is a natural evolution. We need to start working on the things that are in place and having real live people at the table.
 - Karen inquired if anything came out of the Town Hall meeting?
 - John responded that there was a slide show with the history that built up to the recommendation for "The Governor's Commission for Access to Community Based Services" to merge with the SCPD.
 - The Town Hall meeting was held on the anniversary of the 29th Anniversary of the passage of the Americans with Disabilities Act

- (ADA). John had the privilege of accepting a proclamation from Governor Carney that paid tribute to that day.
- Secretary Walker mentioned the importance of including trying to work with better policy and initiatives for dealing with brain injuries.
 - John saw an email a few minutes ago where Secretary Walker indicated that they did not have the brain injury data available. It is going to be very hard for them to move forward without access to data.
 - For anyone who doesn't know Rita Landgraf, she was a former chair of the SCPD and she is being very active in this whole process. Rita Landgraf will serve as a resource even if she is not directly involved as a member or a co-chair.
 - Karen inquired if the SCPD has membership on the committee that the Governor stood up to consider DSAAPD? John responded yes, that Kyle is a member of that committee. John advised that while DSAAPD is being reviewed at the recommendation of the Legislature; it is still the Governor's Cabinet Secretary so it is very unlikely that the Governor will do anything that his Cabinet Secretary does not want.

ADJOURNMENT

- Ron Sarg made a motion to adjourn that Christine Applegate seconded. Tammy called for discussion and hearing none, called for a vote by voting committee members present who unanimously approved the motion to adjourn at 3:32 pm.

NEXT MEETING

- The next scheduled Brain Injury Committee meeting is on:

Monday, September 9 at 2:00 p.m.,

Smyrna Rest Area Conference Room

5500 DuPont Parkway, Smyrna, DE 19977