



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
Margaret M. O'Neill Bldg., Third Floor, Suite 1
410 Federal Street
Dover, Delaware 19901
302-739-3621

The Honorable John Carney
Governor

John McNeal
SCPD Director

BRAIN INJURY COMMITTEE
May 7, 2018 – 2:00 PM
Smyrna Rest Area Conference Room, Smyrna, DE

MINIMUM QUORUM OF 18 NOT MET

PRESENT: Sharon **Lyons**, BIAD, Co-Chair; Sybil **Brown** (for Wendy Strauss),; Andrew **Burdan**, Brain Injury Advocate/Support Group; Donna **Dixon**, Bayhealth Neurosurgery; Katie **Freeman**, DSCYF, DPBHS, Psychologist (for Robert Dunleavy LCSW); Kristin **Harvey**, DDC (for Steve Yeatman); Michelle **Hood**, St. Francis LIFE; John **McNeal**, SCPD Director and survivor; Nancy **Ranalli**, Easterseals, Director of Community Outreach; Dr. Ron **Sarg**, DCVA/MOAA; DLP; Jamila **Waigwa**, DHSS/DSAAPD; and Dee **Rivard**, SCPD.

PARTICIPATED BY TELECONFERENCE (does not count toward quorum): Laura **Waterland**, Esquire, Community Legal Aide.

ABSENT: Linda **Brittingham**, Christiana Care Health System (CCHS); Thomas **Cairo**, Bayhealth Neurosurgery; Kathie **Cherry**, Governor's Advisory Council for Exceptional Citizens (GACEC); Tammy **Clifton**, DOL, DVR, VR Counselor I; Felicia **Connor**, Susan **Cowdery**, BCBS, Highmark Health Options; Jane **Crowley**, Vanessa **Deloach**, DHSS/DDDS, Assistant Director (for Rick Komalski); Debbie **Dunlap**, Advocate, Parent of a survivor; Dawn **Edwards**, DHSS, DSAAPD, Sr. Social Worker/Case Manager; Dr. Gerald **Gallucci**, Program Director, DHSS/DSAMH; Fran **Haggerty**, DOE; Jody **Hougentogler**, BIAD; Laura **Howard**, Deputy Director, DHSS/DSAAPD; Mary **Iampietro**; Nicol **Joseph**; Larence **Kirby**, DOS, Commission of Veterans Affairs, Executive Director; Cynthia **Mercer**, DHSS, DSAAPD, Planning Supervisor; Dale **Matusevich**, DOE, ECE, Education Associate, Transition Services (for Mary Ann Mieczkowski); Maria **Miller**; Carolyn **Morris**, DHSS/Office of Telehealth Planning & Development Medicine; Dava **Newnam**, DHSS/DSAAPD; Jennifer **Oppel**, Ann **Phillips**, Chair, Parent of a survivor; Melissa A. **Smith**, DHSS, DSAAPD, Planner; Tiffany **Stewart**, DOE, Brandywine School District; Clarence **Watson**, DHSS, Medical Director; Leah **Woodall**, DHSS, MCH Deputy Director;

GUESTS

None

CALL TO ORDER

Co-Chair Sharon Lyons advised that we could not hold a meeting due to lack of quorum at 2:15 p.m.

ADDITIONS/DELETIONS TO THE AGENDA

None

APPROVAL OF PREVIOUS MEETING'S MINUTES

Sharon asked if everyone was able to review the minutes of the last meeting calling for any additions, deletions, or changes. While there were no additions, deletions, changes, or discussion on the minutes Sharon announced that approval of the April meeting minutes will have to wait until the June 4 meeting for approval due to lack of quorum.

OLD BUSINESS

- Follow-up Items
DHIN

Review of Katie Freeman's TBI Information

- Katie stated that Tom Cairo inquired in March if anyone had time to put together some ICD Codes for brain injuries and the information she shared provided ICD Codes for the Brain Injury Committee to consider requesting from DHIN. Unfortunately, Tom is not in attendance for this meeting.

Review of Sharon Lyon's Delaware Trauma Systems Registry Information

- Sharon spoke about the information that she obtained listing brain injuries in the state of Delaware from 2009 – 2013 by county, age, gender, race, mechanism of injury, ISS-R, number of patients with an ICU stay and patient status for Type 2 and Type 1 brain injuries.

Review information that John obtained from Public Health

- John stated that Sharon identified information that was previously included as part of the Brain Injury reporting up until 2013. This information is accumulated annually by the Division of Public Health although John has yet to find it in the same format as Sharon's copy.
- John was certain that Karen McLaughlin was going to be in attendance today because she is the designee from Public Health who is statutorily required to attend. There is information available on brain injuries in the State of Delaware that is collected from the various hospitals throughout the state and is broken down in the format that Sharon provided; however, there is actually a much larger format that includes pie charts and additional information.

- While Karen McLaughlin may not have been able to give us the full information he was planning to task her with obtaining this information for us. He stated that hopefully she will resolve this for us at the next meeting.

Tom Cairo to review list of items to include in the Committee's request to DHIN

- This agenda item is postponed until our June meeting since Tom Cairo is not in attendance.

Obtain name of volunteer from Committee to take a more active role with DHIN.

- This agenda item is postponed until our June meeting since the committee was unable to obtain a quorum to hold a meeting.

MEMBERSHIP

- Need someone from the VA - Ron Sarg contacted them several months ago and that person had a substitute and now neither one of them are showing up.
- John McNeal advised that he hopes that we can get this sorted out by our next meeting. John will follow-up again to see who we can get to participate. The standing rule with the council is that if you miss 3 meetings in a row you are contacted to find out what is going on and if there is not an appropriate response then you are dropped from the membership. We can do a follow-up to that organization. He needs to know if they been here for the past 3, 6 months or a year?
- Committee review of attendance/representation from the following organizations was postponed until the June 4 meeting due to lack of a quorum to hold the May meeting.
 - Veterans Affairs Hospital Polytrauma & TBI Program
 - Latin American Committee Council
 - Child Development Watch Program
 - Beebe health Care
 - Point of Hope, Inc.
 - AmeriHealth
 - Peachtree Acres
 - The SAFE Program of People's Place
 - A. I. DuPont Children's Hospital
 - DHSS/Office of Telehealth Planning & Development Medicine

925 REGULATION REVIEW

- When Marika Ginsburg-Block was here we spoke about the schools. Sharon advised that she is now going to be speaking to 7 classes at Red Clay Consolidated School District about concussion and brain injury.
- At the last meeting the committee talked about the DOE document and about what other states have for a traumatic brain injury definitions for IEP.
- Katie stated that multi different classifications are sitting with the DOE attorneys for review and it will come out for public comment in another month or so.

NEW BUSINESS

- Jamila Waigwa inquired if phone attendance counted toward attendance.
- John told the few committee members present about legislation for people to be able to attend meetings by phone and have it count towards quorum. The State Council for Persons with Disabilities would like to see this enforced statewide. Their primary reason for trying to get the full state to be able to do this is that it gives the Council a middle ground to state this is for everyone and settle for a reasonable accommodation of attendance. John reminded everyone that if members cannot make it to the meetings when you are a voting member who is also a state employee that is designated to be here, that there are a lot of people who do not get paid to come to these meetings and some of them travel 6 to 8 hours to ensure that they attend these meetings.

ADVICE

- Michelle Hood from St. Francis requested advice from the group stating that she has a participant who they are having trouble placing because of behavioral issues. This individual has no home because he is not safe to live alone. Any facilities that will take him because he has a TBI are not in the state.
- Sharon actually has 3 people at home that she is trying to find places for due to behavioral health.
- Michelle's patient is currently in a Wilmington Hospital. Michelle stated that they will have to get denials before the state steps in. They are going to have to discharge him from her program in order for the state to take him. PeachTree does not really have a place for him and patients have to be pretty independent in order to stay there. The person that Sharon spoke about actually ended up at Rockford and they do not know how to work with individuals with a brain injury and are not aware that you have to reorient them.
- John stated that we still have Olmstead which requires people to live in the most integrated setting. There are people who get 24 hour care living at home.
- Laura Waterland inquired if Michelle's patient has physical needs or does he just need supervision. Got DSHAM involved previously for another individual for developing placement. It requires arm twisting. He has had a history of cancer and kidney disease. He is sitting in the hospital because no one will take him because of the behavioral issues including his wife. Delaware doesn't have anything at all. Someone asked if he is on the waiver program to which Michelle responded that he is on the St. Francis program which is similar to the waiver program.
- John, many of us are nursing home eligible that are living out in the community in the least restrictive environment. One of the great things that some of our centers for independent living were good at doing were thinking outside of the box to bring all of the resources together in a way that someone is a part of the community. John stated that it is an intermediary issue and a long-term issue with providing rehabilitation which causes people to end up living in other states and never back in the community. There are options outside of the box.

- Michelle advised that he needs attendant care services at home because he is a danger to other people. He already does a day program. It is the LIFE Program in Delaware which is a PACE program. Michelle will contact Laura Waterland to discuss options after the meeting.
- Andrew Burman stated that the option of a 24/7 caregiver is not fundable from the LIFE Program in Delaware.
- DSAAPD does not do overnight care on an on-going basis.
- John advised that Michelle make a referral to the ADRC so the transitions care team can get involved to look at all of the options.
- John requested that Dee send Michelle Laura Waterland's contact information.
- Laura Waterland announced that DE CLASI is receiving a new grant from Social Security to do oversight and monitoring of grant in aids.

ANNOUNCEMENTS

- John informed those present that earlier today there was a TBI Fund Application Review Committee meeting held. The big issue is if anyone is working with family or a survivor of a **traumatic brain injury** the fund still has some money left in the budget that will disappear in June. If there is anything that they would like to request please do so. The committee cannot approve ongoing therapy.
- John stated that Dee will add contact information to the non-minutes for contact information. The TBI Fund Committee has some money that we would really like to be spent by June 15. We asked for volunteers from this committee to participate in the TBI Fund Application Review committee. In the future we are going to see a much better way of doing things.
- There are significant needs for in home modifications. The members or family members do not have the funds to install a chair lift and it is not a covered benefit under Medicaid.
- John advised that we have supplemental funding spending. People need help and we can't make it too difficult. We have people who call the office and have difficulty completing the application. Medicare and Medicaid are two different things. We need to find things that we **can** spend the money on.
- Sharon shared that the Committee has approved bathroom modifications. Renovations are not covered by Medicaid.

ADJOURNMENT

With nothing further to discuss Ron Sarg made a motion to adjourn that Kristin Cosden, seconded before Sharon reminded everyone that this was an unofficial conversation because we did not meet quorum requirements in order to hold an official meeting today.

NEXT MEETING

The next Brain Injury Committee meeting is scheduled for
 Monday, June 4 at the
 Smyrna Rest Area Conference Room
 at 2:00 p.m.