STATE COUNCIL FOR PERSONS WITH DISABILITIES
BRAIN INJURY COMMITTEE
December 4, 2017 – 2:00 PM
Smyrna Rest Area, Smyrna

PRESENT: Ann Phillips, Chair; Linda Brittingham, Christiana Care Health System (via phone); Sybil Brown, GACEC (for Wendy Strauss); Andrew Burdan, Tri BIAD; Tom Cairo, Bayhealth Neurosurgery; Tammy Clifton, DVR/BIAD; Susan Cowdery, MD, Highmark; Vanessa Deloach, DDDS; Donna Dixon, Bayhealth Neurosurgery; Debbie Dunlap, Advocate; Katie Freeman, DSCYF/DPBHS; Kristin Harvey, DDC; Jody Hougentogler, BIAD/Parent Advocate; Sharon Lyons, BIAD; Nancy Ranalli, Easter Seals; Ron Sarg, DCVA/MOAA; Laura Waterland, DLP; John McNeal, Staff; and Jo Singles, Support Staff.

Guests: Michael MacDonald, DHIN
Angela Kaiser, DHIN
Jamie Rocke, DHIN

CALL TO ORDER

Ann called the meeting to order at 2:23 pm. Everyone introduced themselves.

ADDITIONS/DELETIONS TO THE AGENDA

None

APPROVAL OF MINUTES

Ron made a motion to approve the November 6, 2017 minutes. The motion was seconded by Vanessa and approved as amended. Revisions: page 1 – revise: **Ann** did not want… to: **Jody** did not want…..

BUSINESS

Discussion with Michael MacDonald and Angie Kaiser of the Delaware Health Information Network (DHIN)

Ann spoke about Delaware not having a Brain Injury Registry, which impedes us for applying for federal grants that require data collection. She asked the DHIN representatives what is available for data collection. John added that it is difficult to know where we are and where we need to go when data is not available. He looks forward to whatever information they can provide today. Michael stated that DHIN is the Health Information Exchange for Delaware. One of the benefits is that information can be exchanged with providers who sign up for their services regarding patients' lab tests, etc. Delaware is the first HIN (Health Information Network) in the nation. Angie spoke about analytics. She understand that the Committee would like information on how many patients have had a TBI in a year, how many patients have been diagnosed with brain injuries in the past year, and how many people are receiving treatment for brain injuries. Angie explained that they have information on admissions, discharges and data from the provider when patients see them. All hospitals are on board, along with many providers. Angie asked if the Committee was looking for a diagnostic data and where she should be focusing in her comments. Ann asked if the data being

collected is the first diagnosis. She added that brain injury is not always the first diagnosis. Angie commented that if it is not identified in the data they would not have the ability to pull it out. She added that they have natural language processing ability. She said that they could start looking, but it is a slow process. They could look for certain words related to brain injury, for example, anoxia. She would need guidance from us regarding brain injury. Sharon asked about concussion diagnoses. Practitioners know if issues come up later with a patient, it was not a simple concussion, but a brain injury. Strokes are also brain injuries. Tom noted that if strokes are included that would dramatically increase the numbers. He added that the advocacy of the data will be part of the problem. Tom asked if the information is from the medical facility or is the information from claims data. Angie explained that the information is taken from the admission, discharge and transferred data. Angie also spoke about the Clinical Care Document (CCD) that they get from providers, which include clinical summaries. Providers include hospitals, doctors, urgent care facilities and several long term care facilities. Angie noted that all hospitals report to DHIN, including three hospitals from Maryland. They also receive information from most of the free standing imaging centers. They have information on pathology, labs and radiology. Ann asked about consumers accessing the information. Angie explained that the consumer can access information through their Personal Health Record (PHR). The patient portal and provider portal are separate. Vanessa asked about the patient signing a release of their information. Angie clarified that the patient would have to "opt out" so that they do not receive the data. John spoke about issues with the information being available from one provider to another in treating the same patient. Tom explained that the clinical notes will be going to the DHIN. Data on the patient population is going to the DHIN. Some of the data is accessible. Angie added that there is a Community Health Record (CHR) where a doctor can look up information on a patient that they have a relationship with, but not everyone subscribes to the CHR. Also, the records do not come to them until the provider signs off certain documents. Katie asked how it works for a patient who sees three different points of contact due to an injury and if it would count as three different people. Angie stated that they could merge them together. Katie also asked about HIPPA concerns if they "opt out". Angie clarified that their Business Operating Agreements cover all these types of issues. Angie commented that most people want aggregated data so trends can be reviewed, such as population management. Ann asked about collecting data by diagnosis or diagnosis code, or get numbers from trauma or neurology consults. Angie explained that they can cross reference for similar numbers. Data science is taking aggregated data and looking at trends. Angie suggested fine-tuning what we are looking for and talk through this. She added that it takes some time to look at aggregated data, pull results and do Quality Assurance process. She sees this as a working relationship.

Ron asked if the DHIN interfaces with the DOD (Department of Defense) or the VA (Veterans Administration) health care system. Angie explained that they utilize the provider user side, but do not send the DHIN data. Ron commented that at some point, there will have to be an interface. Angie added that are on the path of getting a claims data base. She hopes to have this in the spring or summer, which will clean up the data. It will also give access to medication information. Tom spoke about the fact that TBI can generate from a multitude of injuries and the presenting case may not thought to be a TBI, but results in a TBI at the later time. Angie stated that she saw this as possible, but it would be a matter of clearing different elements.

Ann spoke about important data, for example, age and source of injury. She hopes that it can be expanded beyond TBI and will be a little easier to catch. Angie offered to contact other HIN in neighboring states to see what kind of data the other states are doing. Sharon spoke about working

with the DVBIC (Defense and Veterans Brain Injury Center) about four years ago and they knew how many veterans in Delaware had brain injuries (15,000). Angie commented that the DHIN has an 80 percent accuracy rate. Ann commented that if we were going to fill out a grant application, at least we could say that we were working with the DHIN for data.

Ann spoke about the established protocol regarding concussions and asked if those numbers are received by DHIN. John explained that we are not collecting information from the youth recreation leagues. He added that we have developed a form and training. We will have to do a mass level of outreach to get the word out. He will work with Department of Homeland Security about doing a press release. He added that it would be beneficial to have some level of reporting, but the leagues should have information on concussions. John commented that there may be a way to get this information, including voluntary reporting. It was noted that DIAA (Delaware Interscholastic Athletic Association) is a separate entity. John commented that the Committee's responsibilities were very limited, but he will follow-up on this. He stated that we follow a similar protocol that DIAA uses. Online training for coaches and officials is available through the National Federation of High School Sports (NFHS) Learning Center. Sharon suggested sending letters to those who own the fields (county, city, etc.). John suggested having a sub-committee look at how we proceed. He said that pulling information even later would be beneficial. Nancy added that if protocol is being followed, these children are being seen at urgent care or emergency rooms and receiving tests. Angie commented that is how DHIN would receive the data, but does not know it would be linked back. John commented that these children would be going to a hospital for concussion-related injury, not a head injury. John spoke about the long lasting impact from concussions. He asked why concussions are not considered a primary diagnosis. Angie spoke about the sub-committee looking at ICD-10 Codes, CPT Codes and SNO-med codes. She added that isolating these three codes would be beneficial. Ann commented that all the focus on opioid abuse would also be related to brain injuries. She added that this would be another way of finding data. John asked if the data collected is used at doctor conferences for education in brain injury prevention. Angie commented that analytics is a newer service, but this may be a possibility later. She has seen this done with a consortium of HIE. Susan asked how far away they are from providers running QA reports for analysis. Angie stated about one-two years, but she can run specific queries for reports. Ann said that the Committee have more discussion and then follow-up with them. She thanked the DHIN representatives for the informative discussion. Angie distributed her business card and John gave Angie his business card.

Social Media Option

Tom proposed three possible social media options for Committee members to have a way to communicate with each other and being able to tap into each other's expertise in the normal every day work and the ability to post information in between the monthly meetings. He researched different social media options and came up with the following three options:

- Google Groups (the most versatile and provides the most privacy; it is not public)
- Facebook (works like a web forum)
- LinkedIn (more professionally linked)

Tom stated that all three need an owner of the group and will need to add administrative support on a regular basis. There are different levels of permission.

Tom recommended Google Groups because it is the most versatile and includes online web forums. He noted that it is difficult to switch and add features later. There are levels of how frequently you are notified of new posts (once a week or once a month). John said that it is an additional administrative task. Tom commented that Committee members could monitor the site. Ann asked if this task could be rotated. Katie added that there still can be only one owner. Ann said that she sees this as similar to forwarding emails and people can comment on what is being posted. Ann asked about the facilitation part of it. Tom commented that he sees this forum as inter-Committee only. It will not go out to the public. Administrators would have to add/delete members, tagging key words, setting levels of responsibility in order for this to be beneficial to Committee members. Katie commented that this is a good way for the Committee to communicate and thinks that Google Groups would be best for our purposes. Also, it is separate from the personal page. John will run this through our DOJ Attorney Victoria Counihan before a decision is made. He noted that we are under the State Council for Persons with Disabilities (SCPD) and are a public entity. He mentioned that SCPD has a very active Facebook Page. Tom commented that the public pathway would have to be different from the inter-Committee forum. He offered to meet with people to discuss what we want to initiate here. He added that the owner can designate responsibility and authorization level. Ann thanked Tom for his research and presentation.

Vice-Chair Nominations - Voting

Ballots were distributed and Committee members voted on the Vice-Chair vacancy. Completed ballots were handed in and Ann announced that Sharon was chosen as the Vice-Chair. Ann thanked both Sharon and Jody for their willingness to take on the Vice-Chair position. Voting is not allowed by those calling into the meeting.

Other Business

Bio packets (13) were distributed and will be emailed to everyone. If anyone wish to submit a bio that has not, they can still be submitted and distributed to the group.

Ann would like to put the Needs Assessment done in 2007 on the agenda for February since she most likely will not be able to attend the January meeting. She will also be discussing available resources from other states, etc. that she has gathered at the February meeting related to the Priorities. She also wants to put Priorities from the Strategic Plan on the agenda.

Jody stated that BIAD is happy to publish resources. She also stated that BIAA (Brain Injury Association of America) is doing for Registries. They are pushing the CDC for TBI surveillance information. She noted that CDC has TBI and everything else is under medical.

John spoke about what was discussed with the DHIN representatives about organizing a small group. This topic should be on the next agenda (DHIN Follow-Up). There was some discussion about costs in utilizing their services. John said that we can find out. He also commented on the great turnout today. We could also talk about legislative priorities and look at other funding for the Brain Injury Committee.

ANNOUNCEMENTS

Kristen spoke about the Partners in Policymaking Program sponsored by the DDC (Developmental Disabilities Council). This program is an advocacy and leadership training program for persons with disabilities. The application deadline has been extended to January 3, 2018. Information can be found on the DDC website: https://ddc.delaware.gov. Positive comments were given about this life-changing program. The group meets for eight weekends (1 weekend a month for 8 months).

Nancy stated that Easter Seals still has funding available for Lifespan Respite. Additional information can be found at www.delrespite.com.

Ann announced that the next MCO call from Family Voices will be in Spanish on Tuesday, December 12th.

ADJOURNMENT

The meeting adjourned at 4:08 pm.

Respectively submitted,

Jo Singles
SCPD Administrative Specialist
S: bic/dec17min