

**DATA DEVELOPMENT SUBCOMMITTEE MINUTES**  
**May 28, 2019 – 4:00 PM**  
**Margaret M. O’Neill Bldg. 2<sup>nd</sup> Floor Conference Room, Dover, DE**

**QUORUM MET – 3 OF 5**

**PRESENT:** Karen **McGloughlin**, **CHAIR**, Director of Women’s Health; Christine **Applegate**, RN Navigator, Bayhealth; Andrew **Burdan**, Brain Injury Advocate/Support Group; and Dee **Rivard**, SCPD Support.

**ABSENT:** Thomas **Cairo**, Bayhealth Neurosurgery; Nicholas **Duko**, Program Manager, LTSS, BCBS Highmark Health Options;

**GUESTS:** (Not able to vote or count toward quorum)

**IN-PERSON** – Randall J. Farmer, COO and TerriLynn Palmer, Director of Data Analytics, Delaware Health Information Network (DHIN); DHIN website: <https://dhin.org/>

**TELECONFERENCE PARTICIPANTS:** None

**CALL TO ORDER**

Karen called the meeting to order at 4:10 p.m., thanking Mr. Farmer and Ms. Palmer from Delaware Health Information Network for attending today’s meeting.

- Randy Farmer suggested that reviewing the “NEXT STEPS” section of the last meeting’s minutes was an appropriate place to start today’s meeting.

While Chair Karen McGloughlin agreed with Mr. Farmer, she stated that the first order of business required was review and approval of the previous meeting’s minutes. Karen asked everyone to take a few moments to read over the minutes of the last meeting and let Dee know if they required any changes, additions, or deletions.

- Randy Farmer from DHIN requested a change on page 6 under the 4<sup>th</sup> bullet requesting correction to read:

“Randy advised that Governor’s Carney’s Office and the University of Delaware, Medical Research Department are helping DHIN officially celebrate the unveiling of the DHIN portal tomorrow.” The Committee agreed to the correction of the sentence for clarity of DHIN’s partners in celebrating the portal’s unveiling.

- TerriLynn Palmer from DHIN requested deletion of the third sentence in the second bullet point on page 6 due to the uncertainty of the wording of the sentence making it unclear as to

who the plural possessive pronoun “their” referred to within the sentence. The Committee agreed to remove the sentence for clarity.

- Christine Applegate requested a correction to her title to change it from “EN” to “RN”.
- Christine Applegate made a motion to approve the minutes as revised that Andrew seconded. Dee will make the revisions prior to finalizing the minutes of the April 30 meeting.
- Karen then turned the meeting over to Randy Farmer from DHIN to review and discuss the “Next Steps” from the April 30 meeting.

## **NEXT STEPS REVIEW**

Randy Farmer read the first and second bulleted “Next Steps” from the April 30 Minutes for the DDS and DHIN representatives to discuss the status as of this meeting.

- **DHIN will work on the legal aspects of our request with their attorney and present our request to their Board.**
  - Mr. Farmer agreed with the first bullet point philosophically stating that he recently shared the DDS data request with the Joint Sunset Committee when he met with them. Mr. Farmer believes that state agencies should be able to access the data that the DHIN maintains since the State of Delaware helped to create and was heavily involved in the start-up of DHIN. Part of the way the state recoups its benefits from helping to set up DHIN is to have access to that data. Randy Farmer continued that the DDS data request is part of what the DHIN does. The DHIN charges Public Health for some of the data that they request. Mr. Farmer is a firm believer that there should be a review of redundancies for data requests in order to avoid setting up additional databases. The DHIN must incorporate being compensated for their time into data requests. However, a State agency should have a legal right to the DHIN data services and the DHIN is legally obligated to support that claim. He advised that we know what the spirit of DHINs mission and statutory construct is.
  - When he appeared before the Joint Sunset Committee, he used the DDS request as an example of how the DHIN data could benefit state agencies. The Sunset Committee approved the DHIN restructuring their statute. Unfortunately, the DHIN is not able to complete the restructuring until next January. Randy advised that if the State Council for Persons with Disabilities (SCPD), Brain Injury Committee (BIC) and the Data Development Subcommittee (DDS) members have connections with a legislative

attorney that SCPD could connect with DHIN's attorney, he believes that the DDS could make our request happen this legislative session. The DHIN can support access for any state agency as part of their normal course of conduct for their mission. However, the DHIN is obligated under the Joint Sunset Committee to set up a task force, compose draft legislation and then get everyone together to review and receive approval. This DDS data request is clearly one of the DHIN's driving use cases and he doesn't believe that the BIC/DDS should have to wait that long. He suggested that the SCPD staff work with the DHIN attorney to identify the appropriate language to be added or amended in order to help facilitate the DDS data request happening this legislative session. He stated that perhaps it may be better to amend the DHIN's subsection of Title 16 in order to allow for broader use of the DHIN's data.

- Karen shared that there may be people on the SCPD and Brain Injury Committee team who would find the ability of querying the data useful. Karen told Mr. Farmer that the DDS would refer his suggestion to the SCPD and request our legislative committee to get moving on this request as soon as possible.
- In answer to a question Randy stated that access to community health records would not incur a charge.
- **The DHIN's ability to share data is predicated on keeping requests to a single purpose and walking it through their system in order to obtain approval.**
  - Karen advised that she would like to be able to follow a patient through the life of their brain injury in order to determine whether or not they are receiving appropriate care throughout their life.
  - Randy Farmer advised that the DHIN charges other organizations \$400 annually for this type of data request which is not an overly onerous fee. He also mentioned analytics advising Karen that if the BIC has an ongoing analytics requests the DHIN charges other organizations to set up the organization's initial query, development and testing by charging \$5,000 for those services. The DHIN also charges other organizations \$1,000 for every subsequent report. He would have to work with TerriLynn and her team to determine what is appropriate. TerriLynn advised that there is also a per hour analyst fee.

- Karen questioned how the report mentioned above is different than being able to query the data on the open portal.
- Terri advised that the report that the DHIN prepared for other organizations was an actual report with aggregated data and not something that the organization could play with to see the data by age group or county. The organization would receive the report quarterly with the data tallied annually. The other organization could not drill down on specific individuals.
  - Randy advised that the DHIN culls through both the claims data and the data from the community health to produce frequency counts for inclusive and exclusive criteria.
  - Mr. Farmer shared that he would like to see SCPD get started on codifying the DHIN statute in order to clarify that a state agency has the full legal right to the data maintained by the DHIN and that the DHIN has the responsibility to support the state agency's right to the DHIN data. He believes that the DHIN can continue to work in parallel toward the same goals. He asked the DDS members present to find out what kind of things the SCPD/BIC members would like to be able to discover from the data in addition to the kind of things the BIC/DDS members want to be able to report on. The DHIN needs to know if the DDS data requests are pretty straightforward and easy or if it will incur a heavy lift from their staff in order to fill our request. He thinks that at some time in the future the SCPD/BIC may want access to a live data feed for our requested information.
- Karen stated that while the DDS members have some ideas, they are still trying to wrap their heads around what type of data the BIC needs. For instance:
  - Number of cases,
  - County of origin,
  - Age group,
  - Where the BIC can use the data pull?
  - What do you think the impact is for more efficient allocation of resources?
  - Because of a better allocation of resources could agencies be quicker in their response?
  - Where do these TBIs occur and through what cause?

- If there is a spike in the mechanism of occurrence, the BIC partner agencies could see the issue and allocate resources to help effect a change.
- Karen advised that her second ask from the DHIN will require additional time because the SCPD/BIC will have to follow patients through their recovery.
  - Who would have to analyze that information to see what services exactly were delivered?
  - If areas are found where services were not delivered then the BIC would have to find out why the services were not delivered.
    - Was it a transportation issue?
  - Need to look at all of the factors that prevented survivors from obtaining services.
  - TerriLynn provided an example of a friend from Sussex who had to go to Christiana Hospital to receive treatment. Her insurance coverage enable her to get appropriate transportation in order to go to Christiana Hospital to receive the care she needed.
  - Andrew also shared information on one of his clients who had a stroke and even though he fell and hit his head during the stroke, he did not receive any scans for over two months. Upon completing the scans, the medical providers discovered not one but two brain bleeds – one on each side of his head.

Karen responded that the answer to both questions was yes if the information is properly reviewed. Karen shared that the whole system as it pertains to TBIs is part of what the SCPD/BIC is mandated to do.

- Randy Farmer stated that if it is part of a mandate then legislatively it should be something that the DHIN should supply the data. Mr. Farmer stated that it sounds like the DHIN has a pretty solid base of data available to provide to the SCPD/BIC. He advised that perhaps the SCPD/BIC could obtain their data sooner through an Amendment to an existing bill. Both Randy and Karen felt that it would be great to be able to accomplish this through legislation before June 30, 2019.
  - Randy, Terri Lynn and the DHIN legislative Counsel Scott Perkins along with one or two of DDS members could participate in the meetings to draft the legislation.
  - Karen advised that once they have an idea of what is being asked then the SCPD and Kyle Hodges could work together on drafting the legislation.

- TerriLynn stated that it is important to inform the group with data at the high level statistics. What if requested diagnoses codes were impacting 10% of Delaware's population? The DDS has their numbers. The DHIN hasn't completed their data run yet; however, TerriLynn advised that she will ensure that our initial data is run prior to Scott and Kyle's meeting. TerriLynn felt comfortable in stating that she should be able to differentiate between acquired brain injuries vs. a TBIs.
  - Karen inquired if TerriLynn might be able to map the data so the BIC members would have a map of where TBIs are occurring.
  - TerriLynn responded that if it is an auto accident it might not be paid under typical healthcare insurance. A discussion ensued with most members agreeing that when patients are taken to a critical care hospital the facility bills the patient's healthcare insurance. The healthcare insurance is then responsible to work with the applicable auto insurer to obtain reimbursement.
  - TerriLynn advised that she recently had a chat with the DHIN analyst to see where the DDS request falls within the DHIN working order of requests.
  - Karen advised that with the TBI incident feed it would also be nice to be able to tackle other issues too. For instance, having the type of category for the cause of the TBI would be very helpful. Karen thinks that it is a pass-through type of situation. If the BIC members see large numbers for instance from youth sport's injuries then the data will clearly show the BIC members that we need to work closer with youth sports' groups.
- **The DHIN will determine what sanction our request falls under and whether or not the SCPD will need an interagency agreement.**
  - Randy Farmer stated that this second bulleted item under "NEXT STEPS" related more to the DHIN claims information and felt that their attorney Scott and Kyle Hodges could work this out during their meetings. **\*\*Action Item\*\***

Randy Farmer read the 3<sup>rd</sup> bulleted item under "NEXT STEPS":

- **The DDS needs to send Randy simple statements of the top 10 things that the BIC/DDS plans to do with the data once they receive it.**

- Mr. Farmer advised that he needs sample statements of what the BIC members are looking to do with the data in order for the DHIN staff to work out the appropriate query and obtain the correct data. **\*\*Action Item\*\***
- Karen advised that the DDS needs to go back to the BIC members and request their input statements as to what they are looking to accomplish or look for in the data. **\*\*Action Item\*\***
- **The DHIN's ability to share data is predicated on keeping requests to a single purpose and walking it through their system in order to obtain approval.**
  - The SCPD/BIC request from the DDS members fulfills this purpose because it is requesting data on traumatic brain injuries occurring in Delaware.
- **Do we need to change Title 16 in order to have the DHIN provide the BIC/DDS with data?**
  - Randy Farmer stated that the 4<sup>th</sup> bulleted item under "NEXT STEPS" will be addressed during the meeting between Scott and Kyle. **\*\*Action Item\*\***
- **The BIC/DDS needs to send Randy and TerriLynn a list of keywords to search for in the data that will include words and phrases such as: head trauma, concussion, penetrating head injury, brain injury, etc., that the BIC/DDS is requesting to have included as part of the DHIN data queries.**
  - Karen stated that the top bulleted item on the list provided to the DHIN should be our inclusion criteria.
- **Answer what the financial cost is to Medicaid for TBI injuries.**
  - Karen inquired if the financial data is available so that the DDS members can obtain the costs for Medicaid to the State of Delaware.
  - Randy assured Karen that the financial data would be covered if SCPD has the same rights as the big 4 agencies who already have access to the DHIN data.
  - Karen reminded Randy that Director John McNeal said at the last meeting that the Delaware Legislature already mandated the State Council for Persons with Disabilities to look at data to see where the costs are.
  - Randy spoke about SB 238 from July of 2016 in the 148 GA.

- TerriLynn advised that the kind of inquiry that Karen spoke about would answer the question about the financial cost to Medicaid and the next bulleted item as to the cost to the State of Delaware for TBIs.
- Randy advised that this is expressly why the claims database was set up. The clinical and the claims database will be a treasure trove of information for the SCPD/BIC members.
- **What is the cost to the State of Delaware for TBI cases?**
  - Karen inquired if the financial data is available so that the DDS members can obtain the costs the State of Delaware.
  - Randy assured Karen that the financial data would be covered if SCPD has the same rights as the 4 agencies already legislatively mandated to have access to the DHIN data.
  - Randy Farmer advised the DDS members and Kyle to look at SB No. 238 from the 148 General Assembly in July of 2016.
  - Terri inquired if the SCPD/BIC has an analyst amongst its members stating that the Microsoft Excel App has an analyst add on.
  - Karen kept floating back to the portal, hoping that it will allow people to go in and actually look at the data.
  - TerriLynn believes that the portal is probably one of the best tools that the DHIN has available.
  - In response to TerriLynn's question, Christine Applegate advised that in her current position she takes care of the patients as well as taking care of the numbers.
- **Setup a tentative meeting for 3 weeks out.**
  - Today's meeting addressed this step.
- **Develop regulations on how the SCPD/BIC and the DDS will handle the data it receives.**
  - This step requires the members of the SCPD/BIC, DDS to develop regulations addressing the access that SCPD staff and BIC/TBI members will have as well as what data they are allowed to share and the manner of sharing.
  - Randy Farmer advised that the DHIN has forms requiring execution prior to any data sharing occurring that provide guidelines and standards of acceptable use for agencies accessing the DHIN data.

### **NEXT STEPS – 05/28/19 Meeting**

- Coordinate a meeting between Kyle Hodges, and John McNeal from SCPD and Chief Operating Officer (COO) Randy Farmer and the DHIN counsel Scott Perkins.
  - TerriLynn Palmer advised that she could make herself available to participate in this meeting by teleconference in order to provide additional information as long as COO

Randy Farmer, DHIN Counsel Scott Perkins and SCPD Kyle Hodges were all together in the same meeting room.

- Karen McGloughlin advised that she would also like to attend this meeting.
- Ask each BIC member to provide the DDS Chair one statement that provides an example of what they would like to do with the TBI data.

## **ADJOURNMENT**

- Andrew made a motion to adjourn the meeting that Christine Applegate seconded. Karen called for discussion and hearing none, voting subcommittee members present unanimously approved the motion to adjourn.
- With no further business to discuss the meeting adjourned at 4:45 p.m.

## **NEXT MEETING**

Dee will work to schedule a meeting between COO Randy Farmer, DHIN Counsel Scott Perkins, Director John McNeal and SCPD Legislative Liaison Kyle Hodges within the next two weeks. Depending on the outcome of this meeting, Chair Karen McGloughlin will apprise committee members of the next DDS meeting.

### **Next Meeting**

Monday, June 10

Delaware Health Information Network Office

2:00 p.m. – 3:30 p.m.