DATA DEVELOPMENT SUBCOMMITTEE (DDS) MINUTES
May 19, 2020 – 2:00 PM
Virtual Meeting via ZOOM

QUORUM MET -- 4 OF 4

PRESENT: Christine **Applegate**, RN Navigator, Bayhealth; Karen **McGloughlin**, **CHAIR**, Director of Women's Health; Andrew **Burdan**, Brain Injury Advocate/Support Group; Nicholas **Duko,** Program Manager, LTSS, BCBS Highmark Health Options; and Dee **Rivard**, SCPD Support.

ABSENT: N/A

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

IN-PERSON – N/A

TELECONFERENCE PARTICIPANTS: N/A

CALL TO ORDER

Karen called the meeting to order at 2:02 pm.

REVIEW & APPROVAL OF PAST MINUTES

- Karen called this meeting specifically to determine the questions the Brain Injury Committee (BIC) needs answered by the Delaware Healthcare Information Network (DHIN) data. Therefore, the minutes of the last meeting which met for the sole purpose of working on completing the DHIN, Delaware Health Care Claims Database, Data Request Application were not reviewed or approved.

OLD BUSINESS

- Dee shared her screen to display a report showing data from DHIN on total concussion and Traumatic Brain Injury (TBI) initial encounters seen in emergency departments by year for subcommittee members to discuss.
    - Dee reminded everyone that the reports are confidential as they are not yet completed as per our agreement with DHIN. The data is for the use of the BIC. If anyone else wants to use the data they have to coordinate with the Data Development Subcommittee (DDS) and we have to obtain permission from DHIN to use the data for whatever project the data is being requested for, especially if there are plans to publish the data.

- Karen stated that this is part of the discussion that we need to have especially because Christine is on the Prevention & Outreach (P & O) Subcommittee. When this subcommittee decides that we have the numbers that we want to make public we would turn that report over to the Prevention & Outreach Subcommittee. Karen advised that the P & O Subcommittee probably doesn't want to use the real numbers. She suggested creating percentages and dressing it up by using graphs and pie charts. In addition to the graphs and charts, Karen suggested using Delaware's population which is roughly 900,000 and in 2018 there were approximately 8,828 brain injuries in the State of Delaware which is almost 1% of Delaware's entire population. The P & O Subcommittee would report the percentage of the population in their graph, not the real numbers.
    - Dee shared that what Karen was talking about with the asterisk for 2019 is because the number shown for 2019 does not include a full year's data yet, which is why it looks significantly smaller than the 2018 number. If sharing the data for the year 2019 it would need an asterisk with a notation stating that the data is not complete as of the date of the report since not all reporting entities data was uploaded into the DHIN system yet.
- Karen shared that this is the reason why she previously mentioned that we are still trying to massage the data to ensure that we have it reflecting the accurate numbers that it needs to reflect. We want to ensure that we have captured fully accurate information in each category without misleading the viewer. Karen shared that on the same information graphic that we may want to publish, we could also say that of the percentage of persons with brain injuries in Delaware for the year 2018 that X percent were in this age category or Christine could graph that information with pie charts or line graphs by age or whatever is most readable by the population. Then it would go on to indicate the higher percentage of our prevention going into these areas. Karen shared that the information in the first data report shared is accurate; however, it is not complete; which is why we are saying that it is not ready for publication. This data is not ready for public view because it needs to be placed in context. It needs massaging so that the data does not contain any identifiable information in any way; although she believes that this specific data is generic enough.
    - Dee added that the data is broken down by 10-year age groups, which is nice.
    - Andrew inquired if the numbers in each of the categories and age groups are the number of TBIs in that age group?

- Dee responded no; the numbers listed are the numbers of emergency department initial contacts for concussions, TBIs, and brain injuries. This number is not the total number in the state, it is the initial contact for the occurrence of injury.
- Karen added that the numbers are also not cumulative. If an individual visited the emergency room in 2013 for your TBI or your concussion, and then went ahead and visited the emergency department again in 2014 for an initial occurrence of a TBI or concussion then that individual would be counted again. If an individual did not visit the emergency room again but received ongoing services that is an entirely new category of data that we are trying to figure how to report out. Initially if seen in 2013 the individual would still have that brain injury in 2019; however, it is not reflected in this report because it is not cumulative numbers. If someone asks a DDS member how many brain injuries are in the State of Delaware for any specific time, we are still not able to provide that number. It is very difficult and frustrating.

- Andrew clarified once again that the data showing on the screen is the initial contact emergency room visit for concussions, TBIs and brain injuries.
  - Dee added that the numbers do not include visits to primary care physicians for a concussion because once we include that service provider location, it also includes data on if the individual had the flu, cold, conjunctivitis, and other medical treatments.
  - Karen agreed and stated that they could also end up being counted twice if we included provider locations for physicians an individual could have gone to the emergency room for their concussion or TBI and then subsequently went to their physician both visits would be counted as initial visits/first occurrences for the injury. So, we are really having a tough time sorting through this data and figuring out what the real numbers are.
  - Dee added that what we need from the DDS members is some questions that we can have DHIN try to answer using the data. Dee shared a screen report of Adults 18 – 64 by year by principal diagnosis which was prepared using Excel which is a little more difficult. The reason it is more difficult is the categories include principal diagnosis, other diagnosis 1, other diagnosis 2, other diagnosis 3, and other diagnosis 4 through 12. When attempting to add in other diagnosis 3 data the data numbers decline significantly instead of increasing because I am adding additional information.

- Dee explained the report that she was currently sharing on her screen stating that it shows the data by year. On one of the codes it shows an individual who had a concussion as the cause of the visit; however, it also shows that the patient had edema of the spinal cord, initial encounter. It is still showing a drop in data and 2018 should be a full year of data. This report only shows brain injuries for the first two diagnostic codes.
- Christine explained one of the codes as a contusion or laceration of the head with loss of consciousness and died before regaining consciousness. This code is showing a bad enough brain injury where the patient never awoke from the initial injury.
- Dee reviewed several other codes and totals from the report displayed demonstrating how to read the data displayed in the report. Totals are in bold text to the right of the ICD-10 code with a short description of the code beneath each light blue line. At Karen's suggestion, Dee highlighted one specific code in the report to provide a visual of how to read each code on the report. Each code is at the beginning of its section with totals to the right and the description and breakdown beneath. Dee advised that the first code at the top of each page she will have to manipulate the page breaks in order to have the codes shown on the same page as the description. Nothing just appears because everything must be manipulated into a readable format.
- Karen shared that most people read top to bottom; however, in this report the totals are at the top. At least for this report the totals are displayed in bold.
- Christine stated that she did not think that this was supposed to be this difficult.
- Dee read one of the codes highlighted S066X6A. The description for this code is Traumatic Subarachnoid Hemorrhage with loss of consciousness greater than 24-hours without return to pre-existing conscious level with patient surviving initial encounter. The bold numbers to the left of the code and above the light blue line are the totals by year for that specific code within the age group 18 – 64 in Delaware. With this specific line of data showing no occurrences in 2014 or 2015 and a total of 26 for just this one injury code.
- Following a question by Christine as to if the totals were for all of Delaware; Dee clarified that the totals were for Delaware residents and included state employees

who may live in another state but who are covered by Delaware State employee insurance. These injuries are specific Delaware insurance claims. Dee then scrolled to the end of the report to show the totals for this age group for all concussions and TBIs for Delaware by year for ICD-10 codes for principal diagnosis and other diagnosis 1. Dee read across the totals for the committee members. Dee stated that 2019 data is not included in this report since the DHIN does not have the full year's data entered in their database yet.

- Karen stated that if everyone was not confused enough, there are a few more "qualifiers" for the data that she wanted to share with everyone. Ten years from now we won't have anywhere near as much trouble. However, right now, DHIN is still negotiating contracts with different service providers and groups to collect the data. Therefore, when DDS members look at the 2013 and 2014 data, DHIN did not have all the organizations reporting data to them. So, in many of the charts that we will look at, including the emergency department initial contact spreadsheet, we are going to have a tough time comparing years against each other for probably at least 5 or 6 years. This is because each year is dependent on the data received by DHIN. Until DHIN standardizes who they are receiving data from, what it looks like and what it involves, this subcommittee must be very careful with saying that there has been an X percentage of increase in brain injuries between this year and that year. We must be careful about saying this or anything similar because it may not actually be true. It may be just that DHIN has not received the data or completed data entry on data received from all the applicable agencies during that time frame. So here members can see it well on this graph where you look at 2013 grand total initial contacts for concussion and TBI in the applicable years. The grand total for 2013 is approximately 3,706 and jumps all the way up in 2016 to approximately 11,000; which is a huge increase in just a few short years. Some of the reasons for this is the increase in reporting service providers and changes in the state insurance providers. There are a lot of different groups that DHIN added in 2016 that they did not have reporting in prior years. Also, when the State of Delaware opens the Medicaid Plan for bidding then one insurance provider's data suddenly stops, and a new provider's data begins in the new year. Karen stated that it is not clean data. It is very messy.
- Karen returned to the reason why we called today's meeting in addition to sharing what we have so far by stating that what she is asking members what they want to know when looking at this still rather messy raw data. What questions do we want to ask? What do we

want to know is going on? Karen asked Dee to pull up one of the motorcycle reports for age group 18 – 64 stating that the BIC is working on motorcycle legislation. However, not all concussions and TBI data that DHIN receives has an indicator of how it occurred. If it is mentioned that it involved a motorcycle, then this data is pulled. However, Karen has a feeling that these numbers are very low. Everyone agreed that the numbers were way to low.

- Dee added that what is surprising is the amount of motorcycle injuries for children aged 0 – 17-years 364 days of age.
- Andrew added an ATVs also stating that he feels in the lower age group that there is going to be a significant number of concussion and TBIs that are caused by ATV accidents.
- Dee advised that believe it or not the data is showing that the most significant cause of injury in this age group is child abuse.
- Karen reminded everyone that this subcommittee is only requesting data on brain injuries and concussions. So, while there may be a lot of ATV accidents, these accidents may not result in a concussion or TBI and the same with motorcycle injuries. If we go talk with DMV, which John is doing, and he receives those figures from DMV.
- Dee clarified that John already received the data from DMV and the Office of Highway Safety (OHS); however, he is still waiting to receive the data from the Division of Medicaid & Medical Assistance (DMMA).
- Karen continued that while this data could give us total injuries, it is not necessarily going to give us the numbers of concussions and TBIs because someone can; although, it is unlikely, be in a motorcycle accident and not have some sort of head injury. It is possible.

- Andrew stated that in trying to figure out what data we need for what purposes; the P & O Subcommittee, the numbers that this Subcommittee needs may be slightly different than for other projects. If the P & O Subcommittee is going to the public and trying to do outreach and education then they need to focus on the categories, numbers, and percentages that have to do with educating people concussions and TBIs; which may be different statistics than we would want to give to sports organizations for example. Andrew stated that the data required all depends on the target crowds that we plan to share the information with. If we

are trying to obtain legislative support, then the P & O Subcommittee must gear their data towards something that legislators are going to be interested in using to promote the passage of whatever legislation we are asking them to bring forward. Isn't the data required kind of target specific what numbers we may need?

- Karen assured Andrew that he was correct. Again, that is why we asked the DDS members to meet today. Karen explained that she and Dee have a weekly meeting with DHIN, and we want to bring to them our questions. Our questions can be formatted like: How many brain injuries do we have from falls in the age group 65-years of age and older? Then if the P & O Subcommittee is going to do fall-prevention we could take that information and plug it into our fall prevention materials in order to go out to those age groups and do education on fall prevention. We were looking at the motorcycle data because the Brain Injury Committee is looking at legislation for this topic. That is why we focused on this data. However, we wanted to see what other areas the P & O Subcommittee is looking to do outreach and prevention activities and what data that subcommittee needs. Karen asked Christine stating that she is aware that the P & O Subcommittee has not met in a while because Christine is tied up with COVID-19 issues. Do you know where their focus is right now and what data they want?
- Christine advised that she is honestly not sure. The main information that she was trying to obtain is an overall number by age group of individuals in the State of Delaware with brain injuries. And then she believes that the P & O Subcommittee was going to focus on prevention and outreach for motorcycles and getting the word out about available services.
- Karen advised that what Christine mentioned is another data group that we did investigate. We looked at services and some of our questions included: 1) Where are people receiving services? 2) Where are the services being provided? 3) What are the zip codes of the providers? These are data sets that DHIN is going to map for us; although we have not really seen it yet. They did do a couple of maps where the bigger the bubble represented more services provided in that zip code. However, that is not highly accurate and just kind of gave us a sense. It is something that the P & O could use as a visual guide if you wanted to publish something along these lines and then come up with statements relating to the mapping.

- Andrew questioned if the DDS members previously provided to the BIC members a survey of questions, one of which included: “What do you want to do with this data?” Weren’t all BIC members required to provide a list of what they wanted to do with the data when we received it from DHIN? He remembers the survey distribution being several months back.
    - Dee agreed but advised that we did not receive a lot of responses from the BIC members.
    - Karen remembers that we did not receive a lot of responses stating that it was mostly members of this DDS who responded.
- Andrew stated that as far as services go if we can get the services data by zip code then we would know what zip codes lack services based on high numbers of survivors in a specific area, county, or region. This would help us to know that there is not enough neurotherapy, physical therapy, cognitive, speech therapy, or day habilitation services in the area. Is this one of the hopes that we can obtain this information from the DHIN data?
    - Dee shared that both the member and service provider type zip codes are contained within the DHIN data.
    - Karen advised that this subcommittee will have to figure out how we are going to break it down by type. It might be a color coding for how to visually display the information. Karen felt that we needed to talk to Krishna about this request.

  Andrew shared that if members go to the state website there is a list of service providers for day habilitation services or services for brain injury survivors. There is also a listing for the counties that the service providers serve with many of them stating that they serve all 3 counties in Delaware. However, the provider only has one location in New Castle County even though they are willing to accept patients from all of Delaware. Realistically though, how are the brain injury patients supposed to get to the New Castle County location if they live in Kent County or Sussex County to receive their services. Perhaps the service provider has a satellite office in another county, or they are willing to send one of the staff down to another country just so they can expand their network. Andrew often wonders whether these are true services in all 3 Delaware counties.
    - Karen and Dee agreed with Andrew that if the service provider does not have an office in each of the 3 counties then it is probably not true service in each of the counties.

Andrew continued that if the service provider is in Kent County then they can probably say that they take patients from both New Castle County and Sussex County; although, no very deep into each of those counties even though Delaware is so small.

- Karen felt that Andrew made a valid point in that we need to be careful when we map the services. She clarified that the information is based on claims data and if the provider is registered in the claims data with a New Castle County Office, the provider may have actually provided the service in Sussex County in a satellite office in person and met the needs of the patient. But if the service provider's claims data address is New Castle County it is going to show that he is in New Castle County, which is going to skew our data.
    - To the same point as Andrew was talking about, Dee stated that it is the same way with Lauren Haggerty from BrainLove Neurotherapy whose physical office and treatment facility is in Lewes although she states that she serves the entire State of Delaware. However, the patients receiving her services must be able to travel to Lewes, DE.

Karen continued that we may also have some service providers who serve all of Delaware, but their claims office is in New Jersey or Maryland because that happens to be the address of the company providing their billing services. Karen stated that we will have to ask Terri Lynn about this issue.

- Dee shared that the DHIN data gives the actual provider location including street address, city and state.

Karen stated that DDS members know that we have providers who are from out-of-state and who serve all of Delaware, but the provider location is out-of-state. Karen stated that she is just trouble shooting and throwing out potential issues with mapping the data. She doesn't know that it is an issue. Hopefully not!

- Nick Duko shared that he was thinking that for the P & O Subcommittee that it sounds like there is a lot of work to be done in getting the providers and different offices to report in a specific way. If we are not finding what we need in the data, he wondered if we need to take things back a few steps to focus some energy on educating the providers so they are reporting information in a way that we can obtain actionable data in order to do some stuff with the data. This might involve educating them on what kind of codes that we expect them

to use or ensuring that they actually are registered with DHIN to report the information since Karen previously reported that over the years some providers come on and some drop off. They may not be aware that there is a place to report the information. This might be a good action item – to make sure that providers are aware that there is a way for them to add their data into the system. Over time, this will make the data more meaningful when we are looking at it for projects and reports.

    - Karen likes how Nick thinks and stated that he was right. Karen asked Nick if he was also a part of the P & O Subcommittee to which Nick responded no, he was not and that he was not volunteering to serve on it either.
    - Dee shared that Christine and Andrew are both on the P & O Subcommittee.

- Karen stated that she could see some of the members of the Brain Injury Association of Delaware (BIAD) getting around this obstacle to provide some provider education in some of their outreach efforts. They do education and outreach and they target some of the providers in addition to hosting an annual brain injury conference so she can see BIAD doing some of this. Karen believes that we need to reach out and push this initiative to the group.
- Nick knows that internally with the health plan there are initiatives to get providers to report their information for PEATUS and other measures that are trying to capture the data. He understands what you have is only as good as what the providers give you. Dr. C loves to say “Garbage in, Garbage out!” so if you are not getting the data that we are looking for, we can run as many reports as we want but it is not going to give us what we need. Nick is not saying that we have the ability to incentivize providers to submit their data. But he thinks that there is a lot of passion around this topic anyway and a lot of great ideas that people have. If providers can get invested in what the mission of our Brain Injury Committee (BIC) is, and in helping Delawareans, Nick believes that we can at least get a little bit of movement on the needle in the right direction. It’s not like we can give them $5.00 gift cards each time they enter the data correctly, which is something the health plans might do; but maybe the providers will be compassionate.
- Karen believes that like Nick said there is an altruism that we need to tap into. She knows that report it all, at least from her experience back in the day when she had to deal with any of this in the clinics; there was a carrot and the stick. There is a pretty decent stick as well.

Karen does not know how with Dee mentioning legislation to make the legislation read because the reporting of the information is situational, and we would have to be careful. Karen does like the idea of providing outreach to the service providers and if we could highlight the fact that the BIC is trying to analyze this information in order to make it available for prevention. Perhaps this is sort of an unknown category to the service providers. It would highlight the fact that it is important that they report accurately and completely.

- Christine added that unfortunately, the P & O Subcommittee is small and dwindling so we need to recruit some additional members to this Subcommittee.
- Karen stated that the DDS is also a small group because the BIC is a small group to begin with so she is not sure how important it is to have the P & O Subcommittee focus on this issue as much as it is to have the entire BIC membership focused on prevention and outreach. This is a conversation for all the BIC and then the actual typing and formatting of the outreach educational materials and getting them printed could go to the P & O Subcommittee. Christine agreed. Karen stated that just like with the DDS our subcommittee needs to talk about the details but then the entire BIC gets involved in what kind of data that we need, what kind of questions that we want to ask, and what are we going to do with it and those kinds of things. Christine added: when they respond to our questions. Karen agreed that it was kind of like a second job getting everyone to respond. Nick added that we must figure out the carrot.
- Andrew inquired again if we ever sent out the list of questions. Or, do we know what they are in order to run with the questions that we do have while we are waiting for the carrot to dangle. Karen responded that Dee does have the copies of the few surveys that we received back from the BIC members. Karen believes that there were only 5 surveys returned and she does not remember them off the top of her head; however, Andrew remembered returning an entire sheet. Andrew asked what the entire sheet was about because he remembers there being a bunch of categories. Perhaps that was for something different. Karen advised that he was talking about the same survey questions however, she only remembers 5 being returned and asked Andrew if he remembers his responses off the top of his head or if he has a copy of his survey handy. Andrew responded that he did not.

- Christine asked if Andrew was talking about the spreadsheet that the DDS members provided for the headers or categories of information that we wanted to obtain from DHIN. Andrew responded no that he thought that what he completed was some other questionnaire that the BIC members were asked to fill out with other questions like: 1) What groups would you like to have involved? It may have been specific to the area of brain injury that Andrew is involved in, which was day rehabilitation.
- Dee shared that she remembers what Andrew is speaking about, but she thinks that the only ones who submitted survey responses did not even include the full DDS members. There were some questions that we received; however, Karen correct me if I am wrong, Dee believed that the DDS members decided to set those surveys aside once we learned about all of the restrictions from DHIN on sharing the data. This subcommittee decided to first get the data to see what all is in the data because we didn't know what we didn't know until we received the data. Therefore, everything was put on hold. Dee believes that what we need to start with first is narrow and deep to get an actual true count of the number of concussions and TBIs by year within the state that are initial visits. Then Dee liked Andrew's previous suggestion about getting the provider locations to find out where the provider services are located. Dee stated that she and Karen already saw a map that DHIN prepared of where the provider services were located by provider type; and it was still top heavy with New Castle County with Sussex County showing a few providers that we were surprised to see and then there was were the ones in New Castle County. This is the type of thing that we are trying to narrow the data down to obtain. What is Christine and the P & O Subcommittee going to need to be able to prepare a Delaware specific concussion or TBI educational flyer.
- Karen stated that she agrees with Dee in the first two that she mentioned are probably the topmost priorities. The second issue with mapping the providers, Karen did talk to DHIN representatives about doing this although we have not really received any feedback yet because we have been focusing on the first request. When we start receiving feedback from Krishna about that and start to dig a little deeper as Dee said, Karen believes that we are going to find similar problems with different views and how the data is going to be reported. We can dig deeper into that in order to hopefully come up with some good information to answer that question. Karen asked if the subcommittee wanted to go any further with this

motorcycle data because she does not believe that it is complete, and she is very hesitant about reporting data that is incomplete because it gives the wrong impression. It makes it seem like it is less of an issue than it is. Dee shared that the data that she showed subcommittee members today contained 4 reports of motorcycle data was all just for one age group. The first report showed the data for the principal diagnosis, the second report contained data for other diagnosis-1, the third report showed for other diagnosis-2 and the fourth report showed data for other diagnosis 3 so the data was not all joined together into one comprehensive report like DHIN has a special software program to do. Dee stated that she is somewhat limited in the reports she can compile using only Excel. Dee believes that there is a lot more there than what we saw in the reports that she shared today. Dee shared that she and Karen have requested DHIN to first combine the concussion, TBI, and specific brain injury codes which will then give us better data on the first report that she shared with everyone earlier today for emergency department initial visits. The second thing she and Karen requested DHIN to run was pedestrian injuries E.g. How many pedestrian injuries resulted in a brain injury? It requires a lot of filtering.

- Karen stated that she was unsure if we have anything more to discuss because the purpose of this meeting was to show you some of the data that we have and ask what questions that members had about the data and what questions you wanted she and Dee to take to DHIN. Karen stated that she will pursue the mapping of service providers by geographic availability. We will also get the total numbers of concussions and brain injuries in Delaware that Christine requested. Karen requested all members to give additional thought about the presentation to providers and training of providers because she believes that is a good avenue to pursue. Karen stated that she can potentially talk with Terri Lynn from DHIN to see what her thoughts are as they may have different areas or may even have training already established for their providers that input data into the DHIN system. It could be as simple as adding on to some sort of training that DHIN already conducts. Karen stated that she will have to ask Terri Lynn that question as well.
- Dee inquired if anyone had anything else? Christine stated not at this time. Nick stated that he did not have anything else either. Dee asked members to please submit questions via email to Karen copying her. She asked them to submit any questions that we want to see if the data can answer the question.

- Nick inquired if Dee was going to send out a link to the recording of today's meeting. [**NOTE** Dee tried to send it to Nick but it was too large to send through email.] He wanted to know if Dee could share a copy of the reports that Dee shared on her screen earlier. Dee agreed to send the reports out reminding him that they were confidential to this subcommittee and not to be shared.
- Christine inquired if she was understanding correctly that the P & O Subcommittee is not allowed to use the actual numbers from the data reports and had to use only percentages in their educational and outreach documents. Dee clarified that any area that showed 10 or less members for any specific information could not be shared. Dee provided an example of if we obtained information on the number of TBIs by zip code the data would show that there could be a lot less than 10 people in some of Delaware's zip codes which is considered self-identifiable information. Dee stated that we cannot share actual numbers that are 10 or less. Dee stated that if there were some way, and all this is manually filtered, by us to provide to DHIN for them to run the reports and make it look pretty. If we could figure out all of the zip codes for New Castle County and none of them overlapped into Kent County, the zip codes for all Kent County hoping that none of them overlap into Sussex County, and the zip codes for Sussex County then we could report the data by county. Dee shared that Karen previously had a wonderful idea to try and break the data down by legislative districts; however, they do not have an overlay of zip codes for legislative districts because districts break across zip codes.
- Karen stated that she does not understand how they figure out the legislative districts because there is no rhyme or reason to them. Dee stated that it involves a lot of back and forth and negotiating between the two major parties with both parties trying to draw the districts in such a way that their representatives and senators have districts with the most members of their political parties within their districts. Dee stated that it is a long-convoluted process that is about to come up for redistricting again. Karen shared that she reads a lot of Irish and British history and the process reminds her of the chiefdoms of the early 12th century and how they resolved issues. Karen shared that what she was saying earlier about using percentages, she thinks that we should shy away from giving actual numbers because she questions the actual numbers. Karen doesn't want to say that in 2017 there were for sure 2,362 patients with brain injuries because we would be opening ourselves up

for somebody else to come along and say that: “Well I know that it is not that, it is this number!” If we put it out to the public with percentages, we will have given them the meat of what we want them to know and whatever information it is that we are trying to impart without being held to an exact number.

- Christine stated that we could also use modifier words such as estimated, in such cases, or approximately. Christine shared that she would never comment concrete numbers unless she knew the numbers were her own and that they were clean.
- Karen stated that the DHIN is going to come back to her and Dee with a better understanding because Terri Lynn who is in charge of this project for the DHIN will be able to provide us with a better understanding of what the population base is. Karen stated that she knows that the State of Delaware roughly 900,000 people; however, that doesn’t mean that she is pulling data from the entire 900,000 because she is not. Terri Lynn has certain specific service providers and health insurance companies that she pulls data from and can show that on the screen during our Zoom meetings. Terri Lynn can come up with a certain population that the DHIN is pulling data from so that when we look at the 2013 data, and let’s say that Terri Lynn’s populations during 2013 was 200,000 people before the DHIN added additional organizations and health insurers that they pull data from by the time that 2015 rolled around when it was perhaps 350,000. And then the DHIN added additional service providers, so that if we do the percentages, then it is approximately 2,000 patients based on a population of 200,000 that percentage is like 9,000 patients based on a population of 900,00. She knows that this is getting math heavy in her explanation. What it shows us is that the percentage of population getting brain injuries is not dramatically fluctuating or if it is then we would know that it is not our numbers that are fluctuating, it is actual brain injuries. This is another reason why Karen believes that it is so important to work with percentages because we can eliminate some of our variables that we do not have control over like the population that the DHIN is obtaining data from because it will balance out. Of course, Terri Lynn will use better terms to describe this fluctuation, but Karen hopes that everyone understands the gist of what she is trying to say. Another reason to use percentages vs using actual numbers is because Terri Lynn is not receiving data on the entire population. Correct? Dee stated that the data that Terri Lynn receives is on Delawareans and Delaware State Employees who may live in Delaware or a bordering state but who receive their healthcare insurance from the State of Delaware. It is Aetna,

DMMA, Highmark, etc. Karen stated that if someone has private insurance or if they do not have any insurance at all then there are other populations out there who are not being counted. Dee believes that they are still counted when they go for a visit even if they have no insurance because it is reported in the DHIN data because they are mandated to report the information. Karen stated that we can talk further about this with Terri Lynn because she does not know what the difference is population that the DHIN is collecting information on as opposed to the total population of Delaware. If it is negligible then we do not need to worry about it. Dee shared her screen showing the Delaware population of individuals with disabilities that is available at the bottom of the State Council for Persons with Disabilities (SCPD) homepage that was broken down by county. Dee suggested that perhaps we could do percentage of population by county.

- Karen is concerned about reporting population numbers because someone, will challenge the figures. Karen works the Division of Public Health (DPH) Call Center and stated that the call center receives questions about everything. If we use population numbers someone will question us on the population data.
- Andrew stated that we must start somewhere. We must be comfortable enough with some sort of data and some sort of percentage, from some sort of population, in order to start hitting the streets and doing some prevention and outreach. We must be comfortable enough with at least something or we are not going to move forward at all.
- Karen stated that the information that what Dee just shared on the screen from the SCPD website on persons with disabilities in Delaware they could have just listed the percentage of persons with disabilities they did not need to list the amount of the population and it still would have gotten the point across. That is Karen's point.
- Andrew stated that he thinks that we just need to grab some sort of data and start doing something. We now have more data than we had a year ago. Karen agreed. Andrew stated that there must be some meat that we can feast upon in order to go out and start approaching groups of people even if it is just the number of TBIs in the State of Delaware in the last 4 years. The number that we have not had up until now. Andrew knows that the Brain Injury Association of Delaware for years has been using a number of brain injuries that happened in Delaware per year and that was a number that was borrowed from the national number of people who do report them and then was adjusted based on Delaware's

total population. It was an assumed percentage number. So at least now we are closer. Andrew is hoping that the number that we are coming up with now is greater and shows more significant need for prevention and outreach than the numbers we've been using for advertisement in the past 5-years; as far as need for services than the number of people who have TBIs or survivors of a TBI or numbers of concussions.

- Karen stated that there is a lot of that, and a lot of Delaware's data is like that because Delaware is so small as a state. Karen agreed with Andrew but had to say that Andrew is aware from working in the field, that this is not true. However, if you work in just the data, she is perfectly happy that if she reviews and analyzes data for a year and it comes back and says that we have a low number of people who need these services; she is ok with that.
- Andrew state that he was also ok with that; however, it would be nice to get something that is real and validated.
- Karen stated that we want to be able to tell real data and not an aggregate.
- Dee announced that Nick Duko had to leave to join another meeting. Andrew also announced that he was going to need to drop off soon also because he has another client that he must go visit.
- Karen stated that she believes that we are done now and appreciated everyone connecting with us on short notice.
- Before we leave Andrew asked Dee one more time about the earlier questionnaire that was either handed out during a BIC meeting or something that Dee sent to everyone that asked members to answer a bunch of questions. Those were questions about what to do with data correct?
    - Dee responded that Andrew's recollection was correct; however, we only received 7 surveys back from 24 members. Once the DDS members found out that we could not just get the data and share it, which relates to when Karen talked about developing a request form. However, anyone who wants the brain injury data to use for their own projects, the SCPD BIC is going to have to justify the request with DHIN on a new application stating the reason that the data is being shared. Then it would be considered a team project in that the SCPD/BIC part of, for example, whatever project the organization is planning to do because we provided the data.

- Karen stated that is why when Dee is able to share any data on the screen with the DDS or P & O Subcommittee members like the information that was on her screen today, no member can share that data or information with anyone else or any other groups. It is still confidential information that you cannot publicize it, you cannot put it up on a website or your Facebook page, or talk about it with anyone who is not a member of the BIC DDS or P & O subcommittees. You can brag to your Mom and tell her what a great group we are, or you can talk to your chickens but other than that you cannot discuss the information.

- Andrew asked if any of the seven responses were helpful for the P& O Subcommittee?
  - Dee responded no.
- Karen shared that it all informs to the greater good. It is a process that we are building on our knowledge and understanding of how to use this data and she believes that all of it is feeding into our process of being able to accomplish something here. So, none of it was wasted time. Karen asked Dee to draft notes from this meeting. Karen did not believe that it had to be more than a page or two in order to have something in the record to show that we met.
  - Dee responded correct, the meeting was posted on the Statewide Public Meeting Calendar and that she recorded the meeting. Dee will prepare the minutes after transcribing the recording.

NEW BUSINESS

- N/A

ANNOUNCEMENTS

- N/A

NEXT STEPS

- We need to track the types and frequency of services that survivors receive. While we want to ensure that we do not receive an overwhelming amount of data; we do need to receive data that will tell a story that we can act on.
- The Prevention & Outreach Subcommittee needs to identify hotspots in order to target primary care providers.

ADJOURNMENT

- Andrew made a motion to adjourn the meeting that Christine seconded. Karen called for discussion and hearing none, voting subcommittee members in attendance unanimously approved the motion to adjourn due to other meetings that two of the members needed to join.
- With no further business to discuss the meeting adjourned at 3:10 p.m.

NEXT MEETING

TBD