



2018 Legislative Planning Committee 10/05/18 Minutes

Meeting Locations:

Margaret M. O'Neill Bldg. (**SKYPE Location**)

2nd Floor Conference Room

410 Federal Street, Dover, DE 19901; and

Delaware Developmental Disabilities Services (DDDS) Fox Run

Small Conference Room

2540 Wrangle Hill Road, Suite 200, Bear DE 19701

Total Members:

Required Quorum: 9

Members Present: 9

Members Present: John McNeal (Chair), Susannah Eaton-Ryan, Moni Edgar, Karen Gallagher, Daniese McMullin-Powell, Ann Phillips, Laura Waterland (CLASI), Nancy Lemus,

Members Absent: Stefanie Lancaster, Beth Mineo, Alvin Emory, Laura Greene, Terri Hancharick, Angela Mitchell, Wendy Strauss, Despina Wilson

Support: Dee Rivard

Additional Attendees: William Powell, Sherine White on behalf of Stefanie Lancaster and Ashley (Direct Support Attendant)

Introduction of Members

John called the meeting to order at 10:19 AM. He made housekeeping remarks asking for someone to step in to facilitate if he had to step out. Laura volunteered to step in. Members present at the DDDS Fox Run location and at the remote location via SKYPE conference from the Margaret M. O'Neill Building location introduced themselves with Emmanuel appearing at the remote location to introduce himself and announcing that Sherine White is sitting in on behalf of himself and Stefanie Lancaster.

John announced that at the last meeting there was an oversight where he missed reading aloud Karen Gallagher's remarks. Laura volunteered to read Karen's remarks aloud.

Minutes

John asked for review of the minutes stating that if anyone had a large amount of changes to please give a copy of their changes to Dee. In general the minutes don't have to be this detailed as they are only meant to capture the major points and any decisions made. A suggestion was made going forward to not have the minutes this lengthy or detailed. Daniese, Laura, and Ann will send

Dee a copy of their corrections to incorporate into the minutes for Dee to resend the revised minutes to members.

Review and Development of the 2018-2019 Legislative & Policy Agenda

John directed the committee's attention to review of the 2019 Legislative Policy Agenda. A discussion ensued about Medicaid not holding MCOs accountable and the MCOs not holding providers accountable with several issues discussed.

- CLASI is still reviewing the best approach to this issue.
- Providers think that they can pick and choose whatever they can do.
- Lack of accountability goes all the way down and all of the way up.
- If they are willing to send a nurse then that is providing a service.
- A question arose as to whether or not Medicaid could pay more for complex cases for nursing support especially since weight limits are now being put into place limiting lifting to 30 to 40 pounds.
- The distinction between a home health aide and a nurse.
- Supporting ARP initiative as a committee.
- Not allowing or requiring persons with disabilities to be as forceful as they can because of repercussions. E.g. not having someone who is trained to remove outerwear when travelling.
- Rewording the Nurse Practices Act in order to prevent institutional bias. For example while certain aides can provide medicine in an institution, the same aide cannot provide medicine if the person with the disability lives in their own home.
- Where is the oversight for recent changes in weight lifting requirements? Why are aides no longer able to tell patients when it is time for their medicine or give the patient their medicine?

While one committee member recommended choosing 10 initiatives first and then ranking them, others stated that in the past, all committee members voted for their top initiatives which were then tabulated to determine which initiatives received the most votes. However, this could result in all 3 or 4 of the priority items ending up being focused on one population. It really depends on who comes to the table.

- Children with medically complex issues go through unnecessary denials in order to prove their need and medical necessity. MCOs are mandatory for this situation.
- Questions were raised about why committee participation is so low with a couple of committee members wanting to share the priorities with those who are not attending these meetings. However, John advised that we can only work with the people who show up. We are looking for broader feedback rather than continually seeing the same few people over and over again at meetings that while very passionate advocates are but a small number of advocates out there. Committee members felt that we need to rethink how we are going to address getting more people involved in the Legislative

Planning Committee before next year's meetings. There are topics being discussed that affect all people at all levels. While we have a foundation; Nemours Hospital transitions 700 children per year and the issues being discussed that need addressing cross demographics.

- FOIA affects a broad demographic of people.
- It is helpful to look at the big issues and how many of the topics being reviewed address or fit into the larger issue categories. For instance:
 - Medical issues;
 - Independence and the things affecting independence for persons with disabilities;
 - Why does the adult population receive less service needs than children? We all grow up! Once someone turns 21 there is a broad range of things that drop off. For example providing proper dental care.
 - Freedom of Information Act bias against persons with disabilities.
 - Transportation – e.g. timely, reliable and affordable transportation to appointments;
 - Housing needs; and
 - Civil and constitutional rights.
- John advised that the document this committee is developing is presented at the LIFE Conference. Some committee members felt that the LIFE Conference should have something about housing needs for people with disabilities since the waiting list for housing extends for years. There is a housing conference that Daniese previously attended that requires payment to attend. She advised that it is an excellent conference and that individuals with the power to accomplish things show up at these types of conferences to speak.
- John will share the general topics discussed by this committee at the SCPD luncheon stating that these are the topics currently under review. He will emphasize that we are looking for broader input in order to prioritize these initiatives at a later date.
- Each of the councils have a distribution list and can share the 2019 initiatives requesting them to in turn share the information. We can only proceed with what we have to proceed with.
- Committee members suggested that once the top 3 or 4 initiatives are determined, it would be beneficial to solicit experiences from people with disabilities, their families, and care givers that are relevant to the top initiatives that could potentially help in getting the initiatives supported and passed.
- John advised that he will speak about funding during our Council's budget meeting; however, he is requesting individuals to sign-up to advocate and speak on behalf of persons with disabilities in order to help get funding increased. He will share the dates with committee members and council distribution lists. Someone advised that individuals could also submit written testimony in advance without having to read it aloud during the budget hearing.

Committee members agreed to vote on the legislative and policy issues to determine what the top 10 initiatives are, with the goal of selecting three or four as top priority action items. Legislative Planning Committee members, agencies and organizations should then advocate the larger list of legislative and policy items and use them to educate policymakers and decision makers.

TO DO

Dee will disseminate a word version of the last meeting minutes to Legislative Planning Committee members and collate combined edits into one final document for dissemination prior to our next meeting which will be decided by doodle poll availability.

- Once the top 10 and high priority 3 or 4 initiatives are selected, committee members will work on soliciting individuals to provide their personal experiences either in person, by video, or in writing for the Councils to share with policy and decision makers.
- Committee members are interested in holding a “Legislative Day” where they can make appointments to meet with their legislators in order to talk about the issues that are important to them.
- Committee members suggested joining with organizations such as AARP with whom we agree with on some issues; however, we need to keep in mind that these organizational views are not always our views.
- This Committee needs to broaden our umbrella of entities that have common goals and issues.
- This Committee needs to identify our action items and decide who and what entities we need to bring in to join us in advocating on specific issues.

Other Business – Other Topic Discussions

- N/A

Next Meeting

Committee members decided to hold their next meeting in 2 weeks if members are available. The selection of the next meeting date will occur through the use of a “Doodle Poll” to obtain the most convenient dates this committee meeting at the same locations. The group will review legislative items selected during this meeting for the 2018-2019 Legislative & Policy Agenda.

Adjournment

The meeting adjourned at 11:40 PM.