



2018 Legislative Planning Committee 09/20/18 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: 17

Required Quorum: 9

Members Present: 10

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

Members Absent: Alvin Emory, Laura Greene, Terri Hancharick, Nancy Lemus, Angela Mitchell, Wendy Strauss, Despina Wilson

Support: Dee Rivard

Additional Attendees: William Powell

Introduction of Members

John called the meeting to order at 10:24 AM. Members present at the DDDS Fox Run location and at the remote location via SKYPE conference from the Margaret M. O'Neill Bldg., location introduced themselves.

FOIA

Karen Gallagher raised the issue of FOIA for persons with disabilities. Primarily, why is it a problem for members to participate by telephone? She shared that people with disabilities can't make it to meetings all of the time but are expected to follow the FOIA procedures. John responded directing everyone to the handout of Karen's comments that were provided at the beginning of the meeting inquiring if anyone needed him to read the document. John advised that this is an across-the-board issue and shared that there was actually legislation proposed last year that the State Council for Persons with Disabilities (SCPD) is looking into narrowing. However, due to time constraints, John inquired if committee members could first go through the 2017 – 2018 Legislative & Policy Agenda from last year to try to narrow it down for this year. He inquired as to whether or not committee members wanted to do a 1 - 10 rating of last year's legislative items to see what committee members want to add that wasn't on last year's agenda, such as Karen Gallagher's FOIA issue. Committee members followed their established protocol

in selecting the 2018-2019 Legislative & Policy Agenda. Last year's Voting Topics document contained 22 items. Committee members agreed to start with all topics and issues, not just the left-over topics from last year before narrowing it down to 10 topics with 3 – 4 focus legislative items. The remaining 6 – 7 legislative items that are not focused on for passage during the upcoming legislative session are the responsibility of Legislative Planning Committee member agencies and organizations to actively advocate.

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

John welcomed everyone to the meeting, and directed the committee's attention to the printed meeting materials, which included the meeting agenda, the 2017-2018 Legislative & Policy Agenda from last year, the "Voting Topics" spreadsheet from last year, HB No. 200 As Amended By HA No. 2, HB No. 286 As Amended By HA No. 1, and a print out of Karen Gallagher's comments on the State of Delaware's Freedom of Information Act (FOIA) that Karen requested to include as part of the meeting minutes.

John requested someone to write ideas on the easel as discussed and Beth Mineo volunteered. John asked members if he needed to read the agenda and items being covering today aloud. No one responded affirmatively so John continued.

John felt that 10 legislative items is a lot to work on and suggested that members narrow down their selection to no more than 3 or 4 items for the committee to actively focus on accomplishing. Otherwise it is difficult to obtain support from the legislators and get more than that accomplished during the legislative session. Daniese McMullin-Powell felt that the committee should put all of the items on the wall for the committee to then vote to narrow down the topics. Committee members could then have them in a folder with the main topics talked about as priority. Committee members need to say collectively what we have to work that is affecting the disabilities community and work together to get these items achieved. **The committee discussed the appropriate process, and agreed to develop a list of at least 10 legislative and policy issues, with the goal of selecting three or four to identify as top priority action items. Legislative Planning Committee members, agencies and organizations could then advocate the larger list of legislative and policy items of interest and use it to educate policy makers. The group will work on the shorter priority list with focused action.**

Initiative Removal

As the committee reviewed the documents and last year's legislative agenda, members noted the following:

- **"Funding for Students with Intellectual and Developmental Disabilities (IDD) To Be Able to Attend Certificate Programs Such As CLSC and SEED" --** Committee members advised that this item listed on page 3 of last year's Legislative & Policy Agenda **passed last year.**

- **“Pay Raises for Attendants and Direct Support Professionals (DSP) located on page 1 partially passed last year. Please see further discussion below regarding this issue.**
- **“Access to Quality Preventative Dental Care for People with Disabilities”** -- Following a review and discussion committee members decided to keep this initiative on the list, but to remove the word “preventative” from last year’s title so that it reads “Access to Quality Dental Care for People with Disabilities.” Beth Mineo quoted the Kaiser Report stating that Delaware is 1 of only 4 states that do not pay for dental care for Medicaid recipients. Karen also raised the important issue of having access to accessible dental services and equipment, and adequate transportation for dental services. NOTE: Dental care is usually paid for when a problem exists; however, it is the “preventative” care and cleaning that is not. Committee members shared that transportation is probably the number one issue for individuals supported by their organizations. **This committee needs to advocate about the lack of timely, accessible transportation, Accessible Dental Practices, and Accessibility of Mobile Services.**
- **Elimination of Sub-minimum Wage** – This is an important issue. Laura W. noted that the federal climate around this issue is unstable. **Committee members agreed to list this as an interest item; however, since there is currently no buy-in from the legislative leadership, the committee may not wish to include it as one of the focus legislative priorities.**

Susannah Easton-Ryan noted that the ARC Board has substantial concerns about advocating for either the elimination of sheltered workshops or the elimination of subminimum wage. Implementation of WIOA has led to a reduction in the number of individuals being referred to sheltered workshops. Family members of individuals who are in sheltered workshops are deeply concerned that DDDS will not offer services that are comparable to what sheltered workshops currently provide. There may be common ground if a well-conceived and funded plan to provide alternatives was linked to the elimination of sheltered workshops and of subminimum wage. The view of most of the committee was that, independent of the existence of a sheltered type of environment, alternative funding structures must be developed to support these services other than subminimum wage.

Ann Phillips relayed a positive experience that her son had with a program in Pennsylvania that looks like a sheltered workshop that actively promotes community jobs and pays competitive wages. Ann shared that 3 or 4 years ago she had a meeting with Secretary Landgraf that included representatives from DVI, DDDS, DSAAPD, and the founders of Bakers Industries. Ann shared information about Baker’s Industries, a program in Pennsylvania that looks like a sheltered workshop but is quite different in its operation and attitude. Pay is at least minimum wage. Ann’s son Aaron works 1 day a week at Bakers. They not only give participants jobs they also work with them to help them find a job in the community once they have reached their capacity and would like to advance to the next

steps. Anne's son's told her after his first day of work that it was the first time at a job that he felt respected and valued. This program does not take state funding; they find their own contracts. The State of Delaware was interested in learning more. Rita had asked Dan Madrid who was Director of DVI to follow-up after the initial meeting. He was interested in this model and requested Bakers to work with him as they were willing to share their model. They spoke several times; however, due to circumstances on both sides, it didn't move forward.

John advised that any time there is this much internal opposition, it is better to move on; however, committee members felt that they should add it to the list of 10. Daniese McMullin-Powell felt that the committee must keep this item and not neglect it because it is difficult. People should be given other opportunities not just S.W.S. because exposure promotes interest. **Committee members concluded that while subminimum wage issues are important, the federal climate surrounding it is currently unstable with no buy-in from leadership. Individual member organizations may wish to include it as one of their advocacy focus issues.**

- **Pay Raises for Attendants and Direct Support Professionals (DSP)** – This legislative initiative partially passed last year. Committee members felt strongly about parity pay for HCBS support attendant professionals. Laura Waterland previously did research and advised that the Department of Labor (DOL) has some really good statistics available. Members discussed whether the committee wants to change the wording regarding the McNesby Act that passed and felt that this committee should be able to expand on it. There are not a lot of legislators who realize that what they passed only covers one portion of the population. Committee members felt that there needs to be some sort of parity in pay raises or linking it to a wage study with benchmarks for rate based pay. John advised members that this was one of the challenges the Councils' had last year. The legislation last year was for providers of DDDS services and some of the other programs to obtain funding for their staff. Beth Mineo mentioned a study that DDDS did that contained a language requirement to rebase pay by December. However, it is not funded by any agencies. Committee members felt that there needs to be some sort of parity in pay raises or linking it to a wage study with benchmarks for rate based pay. Reword to expand, link it to an existing study, and prevent institutional bias by recommending that HCBS direct support professionals' salaries are equivalent to DDDS. **To prevent institutional bias committee members advocate recommending salaries for HCBS support attendants that are equivalent to DDDS. Committee members agreed that we need to start with parity across the board. It is important to focus on community services for parity in pay for attendants/DSP across all settings, populations, and providers for both self-directed attendants and private pay, not agency employees.**
- **Accessible Parking** - John felt that focus on this issue this year should be on private enforcement and on holding local governments accountable for their failure to either require

accessible parking spots or enforce parking statutes. None of the counties have completely met their requirements. John felt that the committee should include language that some are not in compliance with the ADA which opens them to someone filing a U. S. DOJ lawsuit due to the non-compliance. The Councils' encountered obstacles and a lot of push back from local Chambers of Commerce, municipalities and Christiana Care; all of whom opposed this legislative initiative as written. John feels the committee could gain more traction by advocating for more people to complain. While this is an important initiative absent of legislation; it is very important to expose those not complying. John believes that the Centers for Independent Living could be crucial in getting people to testify at Leg Hall. Several committee members suggested filing a U. S. DOJ complaint against municipalities, owners, managers, etc. Daniese McMullin-Powell suggested using better language for example: "Having X come into compliance with accessible parking requirements. Neither New Castle County, the City of Wilmington, nor the state typically enforce accessible parking. Karen Gallagher shared that accessible parking spaces are difficult for vans to fit in the spaces since so many others park illegally and the accessible parking spaces do not have sufficient access ways. **Committee members felt that the best path forward is for member organizations to advocate for people to file complaints about any non-compliance.**

- **The Disability Integration Act (DIA)** has gone through several improvements and been known by several different names since 1996. We have all 3 of our federal delegation signed onto the Disability Integration Act; however, it will expire at the end of December. Once again, federal legislators will have to reintroduce it in January or early 2019. Daniese McMullin-Powell stated that many individuals misunderstand the DIA because of how some groups negatively report on it. Daniese shared that currently Medicaid individuals have a right to go into a nursing facility for services; but, do not have a right to get services in the community. The DIA gives individuals that right. *John asked Daniese to put that in writing for the committee.* Had to rewrite to satisfy AARP and the ARC to assure that it does not force people out of institutions. **Committee members agreed to promote information supporting this important piece of legislation next year with a letter from all 3 Councils advocating for Delaware's federal delegates to sign-on and support it again.**
- **Community First Choice Medicaid Option (CFCO)** was put aside after the 2016 election after being available for 5 years and being worked on for 1 or 2 years. Last October, Steve Groff announced that it is being brought back. This is a 1915K State plan amendment waiver, not legislation. It requires submission to CMS for their approval and is in the Federal ACA. **Committee members felt the need to advocate with DMMA for this as a Policy Initiative.**
- **Uniform Standards for Year-round Qualifications for Special Education Teachers – This initiative passed last year.**

- **Amending The Nurse Practices Act** - Laura Waterland shared that the “Share the Care Act” with AARP dropped the idea of nurse delegation because the Board of Nursing is fundamentally opposed to it. The AARP bill would not only allow a family member to package medication, it would allow them to provide instructions to permit a home health aide to provide the administration of medications to the recipient family member, which is not currently permitted under the Nurses Practice Act. The Nursing organizations remain opposed to even this very small change. John advised that there is a new President of the Board of Nursing and suggested that perhaps it is time to get on their agenda.

Laura Waterland stated that the latest bill is so narrow covering aide only agencies and attendant agencies, with the current discussion leaning toward even taking the aide only agencies out. John advised Committee members that they need to create a list of items to develop a dialog with the Board of Nursing.

Committee members felt that supporting the “Share the Care Act” should remain on the list; however, it is important to **work out coordination** with all of the groups. Laura Waterland advised that regulatory issues may present an ADA violation and the issue is being evaluated by the DLP. **Committee members agreed to create a list of items to develop a dialog with the Board of Nursing. The Committee felt that they need to advocate for Medicaid to put in their RFPs to only contract with agencies that offer the full range of authorized services. MCOs are just paying for LPNs instead of RNs. It is Medicaid and therefore it should have parity to nursing homes. There needs to be consistency across HHA agencies and Medicaid needs to enforce it. P.**

- **Funding for Students with Intellectual and Developmental Disabilities (IDD) to Be Able to Attend Certificate Programs Such as CLSC and SEED – Passed last year** as previously discussed.
- **Dual Eligibility - The coordination of Medicaid and Medicare** – Since 2012, it is mandatory for dual eligibles with few exceptions (DDDS waiver) to no longer have fee for service and to use an MCO. **The care coordination necessary to navigate between Medicare and Medicaid guidelines and rules is no longer done.** It is supposed to be the responsibility of the MCO case worker, but they have no knowledge of this or how Medicare works. Due to this lack of coordination many people may not be receiving all of the services they may need or are being told no at Medicare, while being unaware that Medicaid may cover it. Treatment, therapies, DME, and medical supplies are delayed or not received at all due to this lack of coordination. **Committee members agreed to keep this legislative initiative on the list.**
- **FOIA** – John shared that the Councils’ generated legislation last year asking to allow meeting attendees to call in as a voting member that counted toward quorum, which failed. During the process legislative aides for Senator Brian J. Bushweller and Representative Debra Heffernan created alternative proposed legislation; however, John did not have time to

bring it back to the full council for a vote. Plans were already made to reintroduce this legislation this year by Representative Heffernan. John believes that we already have the groundwork in place. He shared that there are already 4 existing boards within the state that allow teleconferencing , without having persons with disabilities involved, so there is precedent for this procedure.

Laura Waterland advised that there are precedents with Massachusetts and California for allowing exceptions to open meeting laws for people with disabilities. Karen Gallagher requested that anything that could be used from her FOIA comments be used for the letter being sent to the Attorney General; however, she requested that it be used generally, not specifically. **The Committee fully supports legislation for a FOIA exception to include persons with disabilities as voting members for quorum in all meetings as a reasonable accommodation.**

Other Business – Other Topic Discussions

- **ATTENDANT/DIRECT SUPPORT PROFESSIONAL CARE FOR INDIVIDUALS WITH DISABILITIES WHEN THEY ARE HOSPITALIZED** -- Laura Waterland advocated for the need to provide compensation for direct support attendants when an individual they are supporting is hospitalized. Attendant/PCA compensation during client hospitalization is akin to bed hold. Additionally, attendants should be available to assist the individual while they are in the hospital. Hospitals don't provide some attendant services and the fund would provide money for aides to assist individuals with having to go to the bathroom, taking care of the person's clothes, etc., **Committee members agreed that funding for direct support attendants to assist individuals with disabilities when hospitalized is an important issue. This may require a separate funding stream in order to avoid double billing issues with Medicaid.**
- **CHILDREN WITH MEDICALLY COMPLEX ISSUES** -- Ann Phillips raised the issue of children with medically complex issues who are being required to needlessly go through reauthorizations and establish medical necessity before having a service approved. Since they are medically complex, this step should not be necessary and frequently causes delay in treatment. Currently, it is mandatory for children on the "Children Community Alternative Disability Program" to have their Medicaid through a Managed Care Organization (MCO). **We need increased oversight of procedural safeguards in Medicaid.**

Currently, the families of children with medically complex care are held responsible for at least one full shift of the skilled nursing care of their children. This is regardless of their ability, (they are not trained nurses) work status, or other family responsibilities. In fact, many parents whose children have medically complex needs are only approved for nursing hours for the hours the parents are at paid employment. The burden falls on them for the other hours. If families refuse to provide skilled nursing care for their child, then their children are considered not safe in their own homes. **Reward to prevent institutional bias.**

Committee members recommend the elimination of needless reauthorizations, the establishment of medical necessity prior to service approval and increased oversight of procedural safeguards in Medicaid. Additionally, families with medically complex care should not be held responsible for providing skilled nursing care.

- **TRAUMATIC BRAIN INJURY REGISTRY** -- John shared the need to advocate for more robust Traumatic Brain Injury (TBI) Registries across agencies.

Currently, without a TBI Registry, our state is unable to receive federally-funded state TBI grants through HRSA. A registry would provide the necessary data to show the grantor the need we have in Delaware.

Initiatives Removed

Committee members present agreed to remove the following items from the 2018-2019 Legislative & Policy Agenda due to their passage or partial passage last year. The FOIA issue is already in the process of being addressed through legislation:

- **Funding for Students with Intellectual and Developmental Disabilities (IDD) To Be Able to Attend Certificate Programs such as CLSC and SEED.**
- **Uniform Standards for Year-round Qualifications for Special Education Teachers.**

Flip-chart easel discussion items from the first meeting.

Legislation/Policy

- Dual eligibility – Medicaid-Medicare coordination
- FOIA exception requirements for persons with disabilities (PWD)
- Attendant/PCA compensation during client hospitalization (akin to bed hold)
- Eliminating family responsibility for providing skilled nursing
- Access to Quality Dental Care
- Accessible dental practices
- Accessible mobile services
- Elimination of sub-minimum wage
- Pay Parity for attendants/DSPs across settings, populations, and provider types (E.g. agency, private)
- Accessible parking
- Community First Choice Option
 - Needs funding
- Amending Nurse Practice Act/“Share the Care Act”

Other Actions

- Expose parking violators
- Demand code enforcement
- Promote DIA (Daniese will write something Re: Right to get services in the community). DIA is a civil right, not a Medicaid issue regardless of funding source.
- MCO Contract should only accept providers that provide full range of authorized services emphasize common sense issues and disparities across service systems
- Pilot Program to carve-out for medically complex individuals and dual eligibles.

John inquired if committee members had any questions or wanted to discuss any other remaining items. Hearing none he moved on.

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 items in order to finalize the wording of the 2018-2019 Legislative & Policy Agenda.

Adjournment

The meeting adjourned at 12:10 PM.