

**FULL COUNCIL MEETING MINUTES**  
**November 21, 2016 - 1:30 PM**  
**STATE COUNCIL FOR PERSONS WITH DISABILITIES**  
***Felton-Farmington Room, DeIDOT Administration Building, Dover***

**PRESENT**

Jamie Wolfe, Chair; Daniese McMullin-Powell, Vice-Chair (by phone); Deb Bradl, DHSS-DVI; Anthony Carter, JEVS; Gary Cassidy, Easter Seals (for Ray Brouillette); JEVS; Sonya Dyer, DAFB/School Liaison & EFMP Family Support; Brian Hartman, DLP/CLASI; Karen McGloughlin, DHSS/DPH; Pat Maichle, DDC; Dale Matusevich, DOE; Jim Miller, Polio/Post-Polio Support Group; William Payne, AAPD; Loretta Sarro, DOL/DVR DODHH; Lloyd Schmitz, Council of the Blind; Todd Webb, DeIDOT-ADA; John McNeal, DeIDOT; Amber Rivard, Support Staff and Jo Singles, Support Staff.

**Interpreters:** Caroline Greene and Tevis Thompson

**GUESTS**

Caroline Cross (for Victoria Counihan, Deputy Attorney General/Department of Justice)  
Lisa Elias – Families Speaking Up  
Terry Macy, DDDS  
Rick Kosmalski – DDC/321 Foundation  
Marie Nonnenmacher - DDDS  
Terry Pepper – DSHS  
Liz Suarez-Gonzalez

**CALL TO ORDER**

Jamie called the meeting to order at 1:35 pm. Everyone introduced themselves.

**ADDITION OR DELETIONS TO THE AGENDA**

- Custie Award Nomination Criteria was postponed until January since Nick Fina could not attend today's meeting
- Addition - Delaware State Fairgrounds Overflow Parking – Bill Payne

A motion was made by Lloyd to approve the Agenda, seconded by Brian, and approved, with no one opposing or abstaining.

**APPROVAL OF MINUTES**

A motion was made by Brian, seconded by Lloyd, and approved to accept the September 19, 2016 minutes as submitted, with no one opposing or abstaining.

**BUSINESS**

**Lifespan Waiver Update**

Terry Macy spoke about the new planning system for people to create their individual plan called "MyLifeMyPlan." This is in compliance with the new Medicaid person-centered planning requirement,

which reflect the needs of the individual. He provided a copy of the My Life My Plan Manual to Jo. He would like to have comments on one sheet in three weeks. He noted that the new way is very different than how it was handled in the past and be more person-centered. Brian asked if there will be a different plan for residential clients vs. day program clients. Terry clarified that the plan would cover both groups. Terry will send the document to Jo electronically. The document will be sent to Council members for review and comments will be collected and sent in one document to Terry. A copy of collected comments will be sent to Council members. Terry distributed his business card if anyone had questions.

Marie Nonnenmacher provided an update on the new Lifespan amendment and distributed her PowerPoint presentation. She provided information including the following:

- Background – Directed by Budget Act to plan for a Family Support Waiver.
- Approach - Amend the current Medicaid HCS DDDS Waiver to create the Lifespan Waiver. This will add new services targeted to families and add waiver slots to include people with IDD (Intellectual Developmental Disabilities) living at home with their family.
- This makes sense for Delaware – Increase Administrative Efficiencies and Enable smooth transitions are needed for change.
- Cost – Expected to be budget neutral for the service costs. Uses current funding of \$1.2M.
- Who will be served? – Individuals already enrolled in the DDDS waiver; those who have left school and who currently receive DDDS Day Services plus new school graduates, and new individuals in need of residential services because they cannot be supported in the family home.
- Waiver eligibility – ICF-IID Level of Care, income no greater than 250% of SSI, and resources no greater than \$2,000. *There was some discussion about excess resources being put into ABL Act Account and Miller Trusts. Rick noted that ABL Act Accounts are now available to Delaware residents.*
- Services included – All DDDS waiver services currently provided and New Family Support Services, including community living support (respite & personal care); community participation; home or vehicle modifications; assistive technology; specialized medical equipment and supplies. *Gary asked for clarification regarding respite and personal care services and what services are currently being given and what respite will look like in the future. Marie explained that there are five (5) provider types that can deliver personal care and respite services. Marie will look into this more and get back to Gary. Also, more than one service can be used, but there is a limit of \$2,700 per individual enrolled in the waiver. Jamie asked about an emergency situation, for example, when an attendant does not show up. Marie explained that a support broker would assist with this and a backup plan would be created. Marie stated that it is built into the RFP for new case management that they have to be available beyond regular business hours. The RFP that will be developed for Support Brokers will have a similar requirement and issued in the spring. They will be contracting with an entity to manage the self-directed option of community living support. Gary asked for clarification regarding the agency choice concept. Marie explained that it is CMS coined phrase—the person hires an agency that manages the employer functions and are a co-employer with the individual who has chosen to self-direct.*
- What is different about how the Lifespan Waiver will be managed? *She spoke about new services: Community Participation (day habilitation without walls) and staffing ratio is 1:2 ratio Person Centered Planning and Case Management. They will also be paying for home and vehicle modifications. There is a limit of \$6,000 per person every 5 years. They will also be offering assistive technology, including cost of equipment and is limited to \$500 per person per year and/or the assessment to determine what is needed and any required training. They will also be covering specialized medical equipment and supplies not covered by Medicaid. The differences on how the Lifespan Waiver will be managed. There are two components: how case management and person centered planning will be delivered. Everyone eligible for DDDS*

*services will have a person centered plan. They will be contracting with an entity to provide case management. They will create a person centered plan. They will create a person-centered plan. Marie clarified that case management is voluntary for those who are not under Medicaid.*

- Person-Centered Planning – A Lifespan Plan will be created for individuals living in a residential setting and a Support Plan for Individuals and Families will be created for individuals living in the family home, and both planning processes are designed to be fully compliant with the CMS HCBS Rule.
- Case Management – Targeted Case Management (TCM) will be available for individuals living in a DDS residential setting (Support Coordinators) and individuals living with their family (Community Navigators).
- Will the staff that support me change? For individuals living in a residential setting – DDS case managers will retain responsibility for case management; for individuals living with their family the private TCM provider will hire Community Navigators to provide case management.
- How routine healthcare needs will be met? For individuals in a residential setting: they will continue to be cared out of managed care and their healthcare needs will be paid fee for service; for individuals living with their family: they will continue to be enrolled with an MCO who will cover their regular (i.e. non-waiver) healthcare needs.
- Can people be enrolled in the DSHP Plus LTSS program and in the Lifespan Waiver? Individuals cannot be enrolled in both the Plus program and the Lifespan Waiver; individuals must choose between the Plus program and the Lifespan Waiver program depending on which program better meets their needs.
- Transition Process (April-June) – In the spring of 2017, DDS will begin: a streamlined, phased in enrollment process; referrals to the Targeted Case Management Agency; information gathering to start developing the person centered plan.
- Implementation date: July 1, 2017 and beyond – After the initial phased-in mass enrollment: as new individuals leave school, they will be assisted to apply for the waiver by their Community Navigator; individuals requiring a residential placement will continue to be assisted with that process as well.

Updated information can be found on the following link (including public hearing schedule): <http://www.dhss.delaware.gov/dhss/dds/>. Public Hearings will be held on November 28, 29 & 30. Marie stated that the PowerPoint presentation given today is on the DDS website: <http://www.dhss.delaware.gov/dhss/dds/>. Marie will send an updated version to the Council and also put it on the website. John asked about eligibility for couples. Marie explained that it would be a different scale for couples, but did not have that information with her today. Brian asked about the 250% federal benefit rate standard but disregard all income. Marie clarified that this is for those individuals living at home and these are post eligibility calculations. If you are living at home, you will not have a patient liability amount. If in a waiver residential setting, there will be a patient liability amount if income as it is counted is over and above the threshold. John commented that this is a disincentive for getting full-time employment since private insurers are not mandated to provide home and community based services and medical equipment. There was discussion about the \$2,000 resource limit, which has been in effect since 1981. John asked how that would work for working spouses. Marie commented about the community spouse resource allowance, of which there is a formula in the Social Security Act, with a \$97,000 resource limit since 1989. Marie commented that when speaking to the feds, they tell them that this is a disincentive to employment. Brian spoke about one area that is becoming more restrictive—up until 2014, children in the DDS waiver allowed as low as age 4 and in 2014, it was changed to age 12. The SCPD objected to that and now the age has changed to age 14 (he referenced page 22 of the Lifespan Waiver Amendment. Marie commented that she did not think it had changed, but will follow-up on the lower age range.

Bill commented about services listed under the Lifespan Waiver, in particular, medical equipment and supplies. He asked if that included repairs and if people could go out of state for the repairs. Marie commented that repairs are included, with no restrictions on going out of state. Gary asked about community living support and another RFP that follows Targeted Case Management. He asked if everything will be implemented July 1. Marie commented that implementation occurs July 1, so Targeted Case Management Agency and the Agency Choice Provider will have to be onboard before that date. Gary asked about provisions being in place for those working in the current system to commit funding for respite events that are scheduled in the summer that have to be applied for prior to implementation; it could create angst for some families. He noted that Easter Seals provides a lot of respite services in the summer, particularly for those on the Autism Spectrum. Most of these events are post-July. Marie did not foresee this as a problem since the available limit for respite funding is currently \$1,500 and will be \$2,700. She suggested that we could make them a priority group for enrollment. Gary spoke about the \$2,700 cap which could be negotiated, based on individual family need. Marie explained that there is an exception process. Gary noted that families needing respite and personal service needs are in a bind with the \$2,700 limit. Brian asked about someone needing a hearing aid which costs several thousand dollars, with an AT cap of \$500. Marie explained that the \$500 cap goes towards the equipment. Evaluation and training to use the equipment is separate. He asked if the person could use the DME standard to purchase a hearing aid. Marie commented that she did not think it would fall under specialized medical equipment because it is specially designed for an individual. They will have to work with DMMA on this (similar to wheelchairs). Jamie thanked Marie and Terry for their presentations today. Comments to Terry's MyLifeMyPlan can be sent to Jo and copies to Jamie and Kyle. Comments will be compiled and sent as one response by December 12. Brian added that he will have his analysis completed by the end of November. The Executive Committee can vote on whether to endorse Brian's analysis.

### **CMS Rule on HCBS – Response to Governor's Letter**

Jamie referenced a letter to Andrew Slavitt/CMS from Governor Markel regarding Request for Additional Guidance Regarding Home & Community-Based Services (HCBS) and Planned Construction (handout), regarding planned construction of "presumed institutional" settings and asking if a state's request for heightened scrutiny be approved before the setting is operational and occupied by beneficiaries receiving Medicaid funded HCBS. Brian explained that a letter was being prepared by Laura Waterland with a more progressive view of the HCBS Rule. Brian recommended waiting for the letter so an informed response can be made. Brian made a motion to authorize the Executive Committee to take action to support the letter or not; the motion was seconded by John, with all in favor and no one opposed or abstaining. Any comments from Council members can be sent to Jo, which will be forwarded to the Executive Committee.

### **Junior Partners in Policymaking Program - 2017**

Jamie provided a PowerPoint presentation on Junior Partners in Policymaking Program for 2017 for youth (15-22 years old) and about 20 people are accepted in the weeklong program. Participants include young adults with developmental and other disabilities. She said that this is a unique program for young people to learn about self-advocacy. She explained the program, including the four reasons to join the program: 1) Learn; 2) Team Up; 3) Grow; and 4) Have Fun.

Jamie reviewed the Program Details, including that it is a week-long residency program developed and funded by the Delaware Developmental Disabilities Council through the Administration for Community Living, the Department of Education and the General Assembly. She described how the week developed. The participants go to Legislative Hall one of the days and give testimony to several legislators; they then receive feedback from the legislators. She reviewed who can apply, participate

and how to get an application or get additional information: <http://ddc.delaware.gov/policymaking.shtml>. This year's program will be held at Delaware State University and will run June 18-23, 2017. Jamie distributed copies of the application. The application deadline is January 13, 2017. Jamie can be reached at [j.wolfe6@icloud.com](mailto:j.wolfe6@icloud.com) or (302) 535-0243. She encouraged sharing this news with folks who might be interested. She asked for suggestions of movies. Amber suggested a movie "Fifty First Dates". Other suggestions can be sent to Jamie. Lloyd suggested moving the deadline to coincide with the LIFE Conference. Pat commented that they will add participants after January 13 if there are available slots.

Karen spoke of her personal experience in the Partners in Policymaking Program. Jim suggested contacting a local television channel (WBOC) for more visibility. Jamie will be at the Transition Conference on December 7<sup>th</sup> and will hold a roundtable discussion with potential applicants. She will also be attending a transition event at William Penn High School. Pat added that bus tickets are provided for participants; they also reimburse for transportation.

## **OTHER BUSINESS**

### **Delaware State Fairgrounds Overflow Parking**

Bill spoke about a letter in the Delaware Coastal Press complaining about the lack of accessible parking at the Delaware State Fair, including in the overflow section. Bill made a motion that SCPD send a letter to the Delaware State Fair regarding a complaint about the lack of accessible parking from the overflow parking and they need to provide accessible parking that meets ADA standards. We could offer technical assistance in regard to ADA. They could increase the amount of accessible parking available in the asphalt section when events are held that provide overflow parking and have alternative trolley service for people with wheelchairs. Pat seconded the motion. The motion was approved, with no one opposing or abstaining. Lloyd suggested that the letter state that the service provider be an accessible provider. (This issue had been discussed at the October Policy & Law meeting). Lloyd suggested that the letter state that the service provider be an accessible provider. Brian suggested that it would be better to have more reserved accessible parking closer to the venue entrance and gave an example of other venues that provide this. John spoke about his personal experience in trying to navigate through the overflow parking at the Delaware State Fair. Todd commented that he thought the Fair uses their own carts which are pulled by car dealerships that sponsor the Fair. He added that the issue this past year was that there was a lot of rain in July which turned the overflow parking into mud holes, but he thinks that under Title III they are required to have accessible parking in the overflow area. John suggested clearly identifying the responsibilities under Title III. Todd will email contact information for William J. DiMondi, General Manager of the Delaware State Fair. Jamie will check with Kyle to see if he or she will write the letter.

### **Polling Places**

Jim spoke about his experience trying to vote on Election Day. His designed voting location is the Lewes Fire Station. The voting lines were blocks long with no accessible parking or anyone to assist those needing help. He drove to Cape Henlopen High, but was told he could not vote there. He saw Senator Lopez who contacted someone who was able to drive him to the Lewes Fire Station and park in an Official Fire House parking space. He was able to vote and get back to his car at Cape Henlopen High within 15 minutes. He added that people should be able to vote at more than one location. People need accessibility. He asked if the SCPD would write a letter to the Department of Elections next year asking for some kind of consideration or ask the legislators to investigate. Pat commented that people could vote in a different place. Brian commented that there is a federal law covering that. He added that every polling place in Delaware should be accessible, including parking areas and route to travel. If the locations are not accessible, they should not be used. He brought up filling out a survey so that the attorney reviewing could contact the person and a complaint could be filed. There is a

complaint process that the State must follow under federal law. Jim stated that he filled out a survey, including his contact information. Jim added that others had similar experiences. Brian added that temporary parking can be set up on Election Day. Jim added that Senator Lopez will be following up on the issue. There is a law that states the SCPD can refer violations to the Architectural Accessibility Board (AAB). The AAB does a site inspection and sends results to the State Election Commissioner. The State Election Commissioner shall defer to the findings. The SCPD is limited to five referrals a year. This was done in 2015. Brian added the CLASI did reports for the April Primary, September Primary and the General Election. They identified deficiencies and sharing them with the Election Commissioner and following up. Several deficiencies were previously noted, but not much is getting accomplished.

## **ANNOUNCEMENTS**

Pat announced that the LIFE Conference is January 25 and encouraged participation.

Karen spoke about a recent meeting of the Governor's Commission on Building Access to Community-Based Services. There is a new form called Preparedness Buddy. She distributed copies of the brochure and stated that it can be accessed through the following link: <http://www.dhss.delaware.gov/dhss/dph/php/preparednessbuddy.html>. She encouraged sharing this information and making plans preparing for disasters.

Karen recently attended a briefing on new autism and developmental disabilities initiatives from the Center for Disabilities Studies (CDS). She recommended connecting with CDS for further information. CDS's CDC (Center for Disease Control) Grant was not renewed, but the initiatives that came out of the strategic planning that created a Plan for Health Equity in Delaware will be moving forward. We are trying to find homes for these initiatives where they can be championed. Many of them will naturally fall under Public Health, for example, health care and emergency preparedness. Another initiative around Data Management ensures that persons with disabilities are accounted for as data information is collected. Karen can be contacted for further information.

Jamie spoke of discovering that the Republican and Democratic Headquarters in Kent County are not accessible. She will follow-up about the other locations in New Castle and Sussex Counties. This could be further discussed in January. She stated that a letter could be sent to the new Chairs of the Committees to see how we can work together to make it accessible.

## **PUBLIC COMMENT**

None

## **ADJOURNMENT**

A motion was made by Lloyd to adjourn the meeting; Pat seconded the motion. The motion was approved. The meeting was adjourned at 3:45 pm.

Respectfully submitted,

Jo Singles  
Administrative Specialist

SCPD/min/nov16