DEPARTMENT OF HEALTH AND SOCIAL SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES

GOVERNOR'S ADVISORY COUNCIL
TO THE DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES

November 18, 2014

The Governor's Advisory Council to the Division of Developmental Disabilities Services met on November 18, 2014, at the 1056 Woodbrook Conference Room, Dover.

COUNCIL MEMBERS PRESENT: Terri Hancharick, Chair
Thomas Rust
Jamie Doan
Timothy F. Brooks, Ed.D.

COUNCIL MEMBERS ABSENT: Angie Sipple

STAFF MEMBERS PRESENT: Jane Gallivan
Marie Nonnenmacher
Vicky Gordy - minutes

GUESTS PRESENT: None

CALL TO ORDER: The meeting was called to order at 1:25 p.m.

NEXT MEETING: January 20, 2015 1 p.m. – 3 p.m.

APPROVAL OF MINUTES: The minutes from the October 21, 2014 were approved.

Feedback on Retreat

The Committee agreed that the retreat went well and unanimously agreed to schedule retreats yearly. During the retreat, it was determined that the following reports be distributed to Council as stated:

REPORTS	FREQUENCY
Vacancy Reports	Monthly
Census Reports	Quarterly & in Advance of Joint Finance Committee Hearings
Budget Report	Quarterly
Applicant Services Report	Quarterly

Council is to receive reports electronically before meeting.

Family Support Waiver

Marie provided the Council with two documents, the Matrix of DDDS Medicaid Services (Conceptual Design Plan as of 11/19/14) and the draft Family Support HCBW Application Development Summary.

The Matrix document reveals a list of all services that are under consideration, what services are covered under each services heading, and notes regarding service differences across different Medicaid authorities. Administrative "services" that need to be put in place to support designated services are listed as well.

The draft Family Support HCBW Application Development Summary identifies the appendices. Marie highlighted and/or reviewed sections of summary. The Family Network Development under Appendix C is considered in an effort to coordinate different family groups. The person centered planning process description falls under Appendix D. The challenge is for DDDS to describe the process that is currently not developed. DDDS has contracted with an individual to develop a person centered planning process, based on the definition of CMS rule. DDDS must provide a projected estimate of cost for the first three years of the waiver for both waiver and state plan services to include an estimated cost of institutional services and state plan services for individuals who may elect to receive services in an institution in lieu of waiver services in the community, describe method used, and estimate the number of individuals to receive each waiver service, the number of units used, and cost per unit under Appendix J.

The draft Family Support HCBW Application Development Summary will be used during the Family Focus Group meetings to begin to fill in the blanks for waiver development. The Home and Community Based Waiver application (recently approved by CMS) is identical for the Family Support Waiver except for the addition of the new Community Rule section. Dates for the two Family Focus Group meetings have been determined and are close to being scheduled. Once meetings are completed, DDDS will provide input from focus group in application to be reviewed by the Joint Finance Committee before submitting for CMS approval.

DDDS is proposing that individuals in managed care continue to be so when receiving family support waiver services unlike individuals who receive residential waivered services who were carved out of managed care for regular healthcare benefits. Eventually, DDDS wants to move individuals receiving residential waivered services back to managed care as well.

Supported Decision Making

DDDS continues to work with the "being a REAL person" group to find an alternative to guardianship for individuals who do not have family to support or legal representation that lack capacity to make consent decisions, determined by attending physician.

Supported Decision Making is allowing someone else to support you in your decisions and to have permission to speak for you. This is slightly different from surrogate decision maker. The purpose is to create an alternative to guardianship, maximize autonomy, and improve health care outcomes for adults with disabilities by permitting adults with disabilities to name supporters to help them understand health-related information and options so they can make their own health care decisions. This approach gives individuals the maximum opportunity to keep their rights with the opportunity for supported decision making when needed. This person may not benefit financially from decisions made.

Life Conference & Prepare Yourself Conference

Life Conference XVII is scheduled for January 15, 2015, at Dover Downs Hotel and Conference Center from 8:00 – 3:45 p.m.

The "Prepare Yourself" Conference for Persons with Disabilities save the date flyer (May 5, 2015 at the Modern Maturity Center in Dover) was distributed to Council.

Charles Bryant attended a session regarding emergency preparedness at the University of Delaware, Centers for Disabilities Studies and returned with tools and ideas to improve DDDS emergency operation plan. The next U of D newsletter will feature DDDS participation.

Disability Day at Legislative Hall

Delaware's Annual Disability Day at Legislative Hall is scheduled for Wednesday, March 25, 2015, from 11 a.m. – 3 p.m. Attendees may preschedule to meet with Legislators.

Judge Rotenberg Center

Council had small discussion and was provided an update.

Housing Vacancies

Currently there are 35 vacancies statewide (4%); 25 in group/neighborhood homes (5 are ARC homes) and 9 in CLA's. Since July 1, 2014, 22 individuals have been placed at chosen site, 11 have chosen placement site and are in process, 49 are shopping for placement in various stages of process, and 21 individuals are placed currently at emergency temporary living arrangements (ETLA). ETLA placements naturally fluctuate; reasons for the recent influx are under DDDS review.

DDDS is working with ARC to build two fully accessible medically oriented homes. Recently, ARC purchased site in Bear to construct one of the homes and continues to search for a site for the second home in southern Delaware. DDDS continues to investigate possibilities of a second roommate at the Justison Landing apartment/condo that was purchased by ARC.

Benedictine has chosen to relinquish providing services in Delaware; homes will be supported by Bancroft.

The Council spoke of a letter to the editor that was in the Delaware's News Journal that gave incorrect information. According to the letter, DDDS currently provides services to 1900 people whose parents are 60 years of age or older. In the past, long-term Council member reported that this number was never higher than 600 and typically 300 to 400, although the age of parents was over 65. The letter gave readers the impression that there are many people without available homes and is making the presumption that these individuals want to leave the family home. Any individuals that receive services from DDDS who fall in high-risk categories are receiving DDDS support. Families may have succession planning in place for family member and when/if time comes for individuals to choose other arrangement, options are available.

Budget

The DHSS budget hearing is scheduled for Thursday, November 20th at Legislative Hall. DHSS is given targeted percentage increases and requests divisional "door openers" to fund services/programs already in place (DDDS special school graduates and placements). DDDS new funding requests include adding dental to the family support waiver, which is in DHSS funding request to the Governor. DDDS is curious about dental funding and wonders the outcome considering that one of the managed care entities are offering dental and the family support group will stay with managed care companies for health insurance.

DDDS Quality Working Group

DDDS has made every effort to achieve for excellence in reports to legislature. DDDS is responsible to write and submit report to legislature and continues to be unclear of the direction. Epilogue language states that the working group report on its findings no later than April 1, 2015. When raised to Rep. Smith, she stated that a preliminary report may be submitted stating that working group has just began, and will continue. Funding may be sought during the next fiscal year to support working group. DDDS Office of Quality Improvement will present what data DDDS currently reflects and a National Core Indicator presentations regarding data collection, with an expectation that DDDS will be required to put information together that is user friendly for families. The legislation speaks to funding based on performance. It is unclear how this is tied to the rate study, as quality was not considered during study. The rate study assumed agencies met certain thresholds and the study revealed an appropriate payment based on services provided. Provider agencies are receiving a 5% rate increase to begin January 1, 2015. DDDS is curious where the 5% increase (meant for the rebasing of direct support professional rates) will be distributed by provider agencies. The idea to request a full and part time pay scale before the increase and a couple of months after increase was discussed.

A few working group members have developed a mission statement that has not been approved to date. Working group participants included the following members/representatives from Homes for Life, The ARC of Delaware, Chimes, Autism Delaware, DELARF, and parents. At DDDS insistence Developmental Disabilities Council and self-advocates representatives were invited to participant in work group as well.

"Villages"

DDDS Director and Deputy Director attended the NASDDDS Annual Conference held last week. A concern was raised regarding building villages for individuals to private pay where parents/families/friends provide natural supports. As natural supports age, resources may no longer be available, which leads to supports not being feasible without payment all while the individual is aging who may require more supports. Once natural and financial supports are extinguished, who provides supports? Will DDDS expect that person to move?

During the NASDDDS Conference, a CMS representative provided a question and answer session. Florida described different types of "Villages" and asked if they would be acceptable. CMS answered carefully, stating you all know that CMS pays for institutional services, then said we believe communities that are intentionally designed to segregate individuals from the general community does not fit the characteristics of community rule (basically CMS will not support villages).

The Village proposal is for very high functioning individuals who may be able to support themselves.

DELARF Retreat

The DDDS Director attended the DELARF retreat last Monday. Legislatures spoke and presentations on rates setting and mental health were held. The mental health presentation was held by the CEO of Connections, Cathy McKay, who gave an interesting presentation. The DDDS Division Director held a break out session where she reviewed the projects DDDS is working on currently. During the break out session, the DDDS Director also spoke of the recent NASDDDS meeting she attended and provided information received from a question and answer session with CMS to attendees. During the CMS question and answer session, it was revealed that CMS and other colleagues are hearing from families that provider agencies are telling families that their sons and daughters will be sitting home, as there will no longer be day services due to the community rule. The Division Director told DELARF members that if they are participating in telling this to families, to refrain. It is not the intention to eliminate services but to change how services are being delivered (per CMS). The Division Director said that she does not think that congregate services are going to be eliminated, but the delivery of the service is going to change and have different expectations; therefore, business models will need revisions. There must be more access to community and more person centered approaches. Smaller settings are inevitable and proven to be the best practice. If Delaware, as a State could begin to look at using plan to come to consensus at how and what will be measured to determine success of a service based on individual outcomes, it would make a huge difference. There is currently no planning for individuals supported by families, who are 70% of the DDDS population.

DDDS intends to adopt and encourage CMS to encourage their adoptions of the new definitions and that they become the norm for pre-vocational and day services; therefore, if you would like to continue to offer pre-vocational activities, where and how you deliver will become the key piece. The community rule is defining a set of expectations. Providers shared that prep work has commenced surrounding transition planning in terms of the community definition.

The Council requested to receive a synopsis of DDDS/DELARF quarterly meetings.

CMS Rule/Transition Plan

The transition plan is currently the primary focus of DDDS. The Division Director and Deputy will review other approved state plans to assist in developing Delaware's plan. Once complete, DDDS will review with a small focus group then place before public for comment before submitting to CMS, no later than the March 17th deadline. DDDS is in a good place, due to group homes in Delaware being relatively small.

At the NASDDDS Conference, during the CMS question and answer session, it was obvious that states are becoming frustrated, as plans are not being approved for transition. Alabama's DDDS director developed a transition plan by comparing state rules to the expectations of transition plan, including the intent to create smaller homes and submitted to CMS for approval. CMS responded by stating to remove any references to the size of homes. Everyone, including CMS was unsure why this response was received. Due to inconsistencies within CMS, states are becoming more frustrated and are experiencing compliance issues. To date three transition plans received CMS's approval, nationally. Ohio presented difficulties, which led to having a service package placed on hold since June due to transition planning. District of Columbia currently has no day services for elders or individuals with brain injuries due to CMS not approving plan. The transition plan must receive public comments when any changes occur, which delays receiving CMS approval.

During the NASDDDS Conference, CMS assigned specific team participants to review definitions surrounding day services including adult day health and day services in an effort to assist CMS to provide guidance surrounding day services. When team inquired about reviewing day habilitation service definitions, CMS told team not to review day habilitation due to not being utilized frequently. This led to team bringing the NASDDDS report surrounding the billions of dollars used for day habilitation services to advise CMS. It appears that CMS is attempting to write a widespread, standardized rule for people that attend any type of day programing, including elders.

Council Chairperson revealed that a group is being established surrounding the Community First Choice option, which is covered under the Community Rule in the 1915(k) option that is defined by CMS as a home and community based setting that must be compliant before submitting for CMS approval.

DELARF was approached suggesting following the best practice model of agencies employing a Medicaid Compliance Officer.

Discussion of DDDS providing speakers to assist families to understanding different service deliveries and the positive repercussion of moving services to a community level was had. This may be a possibility.

Announcements and Informational Items

No other announcements or informational items were discussed by Council.

Adjournment

The meeting adjourned at 3:15 p.m.