Autism Commission

Adult Sub-Committee Meeting Minutes

November 2, 2018, 11:00am –1:00pm

500 Harrison Avenue

Present: Kathy Sanders, Janet George, Carolyn Kain, Maria Stefano, Dianne Lescinskas, Lea Hill, Nancy Marticio, Olga Yulikova, Cynthia Berkowitz, Michelle Brait and Beth Zwick.

**Review and Discussion of Minutes and Meeting Schedule**

The minutes from the September meeting were reviewed and were approved unanimously.

The chair of this subcommittee discussed changing the length of the meeting time to 90 minutes. This subcommittee had been meeting for 2 hours to discuss recommendations for the annual report but will now meet for 90 minutes every other month. A doodle poll will go out to the members to reach a decision on future meetings that will accommodate most.

Olga Yulikova from the Executive Office of Elder Affairs has joined this subcommittee to help address recommendation #2. Ms. Yulikova discussed having EOEA come to a future meeting and do a presentation on their services.

This subcommittee submitted three (3) recommendations to the Autism Commission and there was no vote at the meeting – only a discussion. The secretary asked all of the subcommittees to look at their recommendations and the state agencies involved will come up with a cost estimate of each recommendation and submit the information prior to the December Autism Commission meeting.

**Discussion of status of recommendations to the Autism Commission and development of action plan for each recommendation**

1. *Families of 20 -30 year-old individuals with ASD (and no ID) who self-isolate in the family home need assistance and consultation services to help their adult family members to engage in their communities. DDS in collaboration with DMH develop and implement a family consultation initiative to address that need. This initiative would allow families and individuals with ASD, regardless of DDS or DMH eligibility, to have access to specialized expertise and technical assistance to address the needs of this segment of the ASD population. DDS and DMH will report annually to the Autism Commission on the implementation of this initiative.*

* The age group (20 -30) is addressing the transition aged young adults as they just left school and have a strong desire to stay in services with their age group and are more likely to engage with others
* This is for individuals whether they have been deemed eligible or not eligible
* There is a need to provide technical assistance to family members
* This recommendation relates to a pilot program (metro and northeast region) that is being offered through DDS and will help inform this work – there is a budget for the pilot program that will be used to help do a cost estimate on this recommendation
* DDS is gathering information from families on how to engage individuals and the supports needed
* This subcommittee is interested in the clinical knowledge on strategizing how best to engage individuals who have self-isolated and Cynthia Berkowitz from DDS will assist – Dr. Berkowitz discussed that it is critical to first prevent social isolation and there is an impact on brain health when this occurs

1. *The Adult Subcommittee will work with the Executive Office of Elder Affairs (EOEA) to gather information regarding that agency’s involvement with aging individuals presenting with ASD, and collaborate with EOEA to ascertain if individuals with ASD known to or served by EOEA are aware of other services that may be available to individuals with ASD, and to ensure that EOEA’s network of services are aware of the needs of individuals with ASD and receive training on how to address these needs.*

* The ARC is doing a series of conversations on ASD and aging – they are looking at the gaps and discussing needed resources – this is a grassroots effort and not official
* We don’t have a handle on older adults with ASD and there may be different types of trainings (for vendors) that need to happen to address the need once it is assessed
* There is a movement in other states to allow ASD individuals to live with parents in Assisted Living and when the parent passes, the individual is allowed to stay – could EOEA look at this model?
* Having EOEA on this subcommittee is a good first step on accessing the needs of ASD individuals and aging – once this subcommittee becomes more informed of the services being offered by EOEA there will be further discussion on training and outreach

1. *DDS, in conjunction with DMH and MassHealth develop and establish specialty ASD adult services that are designed and staffed to meet the needs of adults with ASD who present with severe challenging behaviors, including but not limited to; Day-Habilitation services, Community-Based Day Support services and other types of day services and specialized clinical support services necessary to effectively serve these adult individuals.*

* It is a challenge to establish a cost on specialty services – no idea of the need and it is unknown the size of the population
* This subcommittee discussed looking at the model at Bridgewell as a building block for this recommendation
* Bridgewell is successful due to the environment it has created for these individuals and the low staffing ratio
* Bridgewell has 2 programs and works primarily with ages 22-28 with spacious classrooms, technology that includes ipads, non-florescent lighting, special carpet, a curriculum that works with different levels of need and includes a clinical piece, low staffing ratio, employment support services – the population is ASD and ID and the cognitive impairment varies with the individuals
* Individuals also have wrap services from MassHealth (funding) and the curriculum follows MassHealth regulations of ADL skills, communication – they build the curriculum on the need areas and BCBA’s are involved
* Bridgwell currently has about 110 individuals being served and they are mainly transition age (22-28) and also has one individual age 40
* Bridgewell total cost estimate for one individual is $50-60,000 and that does not include transportation costs
* The providers report that the current delivery of allocation is not caught up to the current changes with the Omnibus Law
* Day Hab. is one service and more of a medical based model – Community Based Day Services is another and the level of clinical support was not built into the rates to provide proper staff ratio
* Many providers are running programs in deficit – the service delivery system has not kept pace with the needs
* Parents of individuals in Day Habilitation are demanding that that their individuals are out in the community but MassHealth regulations are focused on habilitative services and not community based
* This will require collaboration with DDS and MassHealth and they will need to develop appropriate rates for this population – discussion on the 11 15 MassHealth waiver and if it could be an option
* This subcommittee will invite MassHealth to the next meeting to discuss this recommendation
* This recommendation was carried over from the 2013 report and no action has been taken thus far
* There was a brief discussion on self-direction funds through DDS and how it is being utilized with the “newly eligible” population who also have challenging behaviors – there have been issues with DDS approving ABA – Ms. Brait will further elaborate on this point

**Revisiting of recommendations from Healthcare Subcommittee referred to the Adult Subcommittee**

Ms. Kain read through the recommendations that were passed on to this group from the Healthcare subcommittee. They thought these recommendations were more appropriate for this subcommittee to review and possibly take action.

1. AFC – this is an issue that is being dealt with on many levels already. AFC requires more hands on assistance and ASD doesn’t require that in some cases but would require more prompting and queuing.
2. AFC and Single Parents as a Guardian – The guardian cannot be the AFC so in a single family household this excludes the parent if they are the guardian.
3. Respite – MassHealth provides PCA/AFC but not respite – there is no funding for respite. DDS does have funds for respite and there is a stipend available through Family Support. This is an issue of having MassHealth evolve and meet the needs of this population.

Rates: AFC – pays $50 per night – DDS – pays $200 per night in your home. EOEA has some respite and will gather more information on this topic. The ARC reported that respite is the #1 gap in services.

1. HCBS – funded through a MassHealth waiver but federally regulated – need clinical level of care to be found eligible and the “newly eligible” cannot meet that requirement. A new DDS waiver is not being developed but could be in the future.
2. DDS Eligibility Tools – Ms. Kain is in discussions with a psychologist about the tools currently being used and that they may not target the “newly eligible”. A tool may not exist currently to meet that need. She will follow up with this subcommittee on this issue.

**Actions Items**

* A doodle poll will go out to subcommittee members to find a date for upcoming meetings.
* Invite a representative from MassHealth to attend a meeting and discuss relevant recommendations.
* DDS will provide this subcommittee with information on their Pilot Program (self-isolation) and their efforts on engaging with families, along with the cost estimates for both.
* EOEA will present at a future meeting to help this subcommittee better understand services they offer.

With no further business to discuss the meeting was adjourned.