**Autism Commission**

Adult Subcommittee Meeting Minutes

May 13, 2019, 12:30 p.m. – 2:30 p.m.

500 Harrison Avenue, Boston, MA

Present: Christine Hubbard, Dianne Lescinskas, Lea Hill, Carolyn Kain, Kathy Sanders, Janet George, Joshua Greenberg, Rita Gardner, Maria Stefano, Liz Martineu, John Randall, Maureen Vibrot and Dania Jekel

Remote Access: Michelle Brait, Chris Supple, Beth Zwick and Olga Yulikova

**Remote Participation - Review and Approval of Minutes**

Christine Hubbard stated that the meeting was subject to the Open Meeting Law and that the subcommittee members present would need to vote to approve the remote participation of some members because of their geographic location, whenever any members were utilizing video and/or teleconferencing. Remote access was approved unanimously by the subcommittee members present.

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

**Presentation from EOEA Services with a focus on housing**

Ms. Yulikova discussed having Victor Hernandez, from DDS, involved in Elder Affairs housing discussions. The presentation will be moved to the next meeting of this subcommittee on July 24th.

**Discussion of Specialty ASD Adult Services**

Providers from Amego, Melmark and Nashoba Learning Group were invited to this meeting today to discuss adult services 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, Community-Based Day Support services and other types of day services and specialized clinical services necessary to effectively serve these individuals. It was discussed that this subcommittee would benefit from a representative from MassHealth. Ms. Kain and Dr. Sanders will reach out to MassHealth regarding representation on the subcommittee.

The providers serve adults and children with high behavior needs and some medically complex individuals. Most are in residential but some are with families.

Behaviors that occur at these centers include:

* Severe aggression
* Self-injurious
* Severe pica
* Bolting
* Flopping
* Fire setting
* Aversion to young children
* Severe communication deficits (some are highly verbal but won’t communicate when upset)
* Feeding disorders
* Significant sleep disorders
* Biting
* 80% have co-occurring disabilities (ASD with mental health issues)

This work requires a sophisticated staff to visually assess individuals for medical issues.

There are many workforce issues and a lot of training goes into new employees – 6- 8 weeks of training per year – turnover is very expensive. There was discussion around paying higher rates to maintain the workforce. A lot of the workforce are immigrants and are non-credentialed. Most organizations will fundraise to fund the staff. Many workers opt to work with children since there is a higher pay rate for children and workmen’s compensation is very high due to staff injury. There is a lack of access to BCBA’s for adult services, most want to work with young kids or do not want to work weekends. It was also noted that even though individuals are in the community, they are still isolated and surrounded by staff. Some congregate settings would be helpful – one size does not fit all and different models would be helpful.

There are different pay rates: A rate is 1:1 support, there are B and C rates. DDS is looking at establishing an additional rate that would fall between A and B (called I rate) and would be for an individual with challenging behavior but does not require 1:1 support 100% of the time.

There was discussion around the low number of providers available to work with those with higher acuity – the majority of the individuals are men with severe behaviors and they are hard to place. It was said that individuals with this level of presentation need to be grouped together or spread out to more providers. As an example, pica requires a high level of staff training and a certain level of space needed with more staff involved and trained.

Rita Gardner discussed the modifications that they have done to their homes on almost every facility. They do private fundraising for capital expenses.

* Reinforced walls
* Special lighting
* Bathrooms with floor drains
* More space in bedrooms
* Space for a gym

There was discussion on what is being done, or not done, in the public schools. The average age that these providers may see some of these individuals is around 13-14 years old. If they would get them at an average of age 8, and have them stay for three years, they would be able to transition them back to the public schools. Schools may be placing Band-Aids on issues and then they accelerate – parents sometimes then drop off in emergency rooms. Communication and language is a key factor in helping the individuals with behaviors. Schools lack in training of AAC devices. The providers have been very surprised at the number of students they receive, at age 13 or 14 years old, that have not been toilet trained. Schools put minimal demand on the students so the behaviors are low due to low demand and there is a lack of skills.

There was a discussion on the lack of good psychiatrists to help treat some of these individuals. DDS and DMH discussed the three fellowships that they are funding to address this issue and intended to help increase the numbers in psychiatry.

Jeanne Hoerter from AANE will be invited to present the results from the recently completed AANE Needs Survey at the subcommittee's July 24th meeting.

The pilot being run by DDS and DMH to address anxiety/self-isolating among 20-30 year olds with ASD not eligible for DDS or DMH services will be completed at the end of June.  The subcommittee will hear a report about the pilot and lessons learned at its September 11th meeting.

**Next Meeting**

Olga Yulikova and Victor Hernandez will present at our next meeting on Housing – Elderly and Assisted Living. The subcommittee will brainstorm some questions on assisted living for individuals aging with ASD.

**Upcoming Meetings**

July 24th – 10:00 a.m. – 12:00 p.m.

September 11th – 10:00 a.m. – 12:00 p.m.

With no further business to discuss, the meeting was adjourned.