**Autism Commission**

 Adult Subcommittee Meeting Minutes

September 11, 2019, 10:00 a.m. – 12:00 p.m.

500 Harrison Avenue, Boston, MA

Present: Christine Hubbard, Dianne Lescinskas, Lea Hill, Carolyn Kain, Joshua Greenberg, Cynthia Berkowitz, Lea Hill, Maria Stefano, Nancy Marticio, Beth Zwick, Allan White and Dania Jekel

Remote Access: Kathy Sanders, Michelle Brait and Janet George

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

Carolyn Kain 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 July meeting were reviewed and were approved unanimously.

**Discussion regarding results of DDS/DMH pilot program for young adults with ASD who are self-isolating and next steps with respect to this program** (from the Autism Commission Recommendation)

Lea Hill and Maria Stefano presented their findings of the pilot to this subcommittee. This work is on-going. DDS and DMH conducted a pilot program from January 2019-June 2019, to address the needs of 8 individuals (5 males and 3 females – ages ranging from 20’s – mid-40’s) with ASD who were self-isolating at home, each individual received up to 10 hours a week of services (direct and indirect), meetings were held every 2 weeks with providers and in consultation with DMH. Seven (7) individuals consistently engaged throughout this pilot program.

* Individuals were from the Northeast and Metro region
* They engaged with master level staff with knowledge of mental health issues and access to a psychologist from DMH
* This pilot was looking at the service gaps for individuals living with ASD and no IDD
* There were consistent meetings between the providers and staff from DDS/DMH to discuss individual progress
* Most individuals wanted social connections
* Not everyone used the full 10 hours per week and some never missed an appointment
* These were pre-coaching services to help individuals move on to DDS coaching services
* Many individuals suffered from severe anxiety and it took a while to engage – the coaches were persistent
* The agencies collaborated with family members
* Flexibility of coaches was very helpful – they also used technology to communicate with individuals
* Many individuals that participated share that they have a large fear of bullying and a fear of being judged in the community – this caused a lot of the isolation – discussion around individuals suffering from post-traumatic stress disorder due to bullying in school/community and isolating out of fear, protecting themselves
* Trust between the coach and individual was most important
* Many of the families felt hopeless – one provider helped a mom build back her confidence in helping her loved one
* Discussion around episodic needs of individuals and the challenge of contracting for those needs
* Discussion on providing flex funding for the individuals to attend community events
* Discussion on the high burnout rate for staff
* Some of the individuals from the pilot had previous psychiatric admissions

Some of the recommendations that may come out of this pilot are as follows: (these will be for coaching features)

* Non-direct service hours
* Staff to have clinical experience with ASD and mental health
* Increase of direct service hours
* Engage with family members
* Measurable objectives of success

Ms. Jekel discussed AANE’s Life Net program which involves intense case management and this subcommittee will learn more about this program at our next meeting. She suggested a recommendation of another pilot program helping individuals live independently so families can step away. Ms. Kain talked about case management for individuals and having discussions with MassHealth about this type of service.

For this recommendation, DDS and DMH will explore how to implement this program beyond the pilot status.

2. 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 subcommittee now has representation from EOEA to assist with this work
* The work is ongoing
* There was a comment that this work is important but not the biggest need for folks
* There needs to be more education for the parents of older individuals
* Autism Support Centers could be a potential resource for families – there could be encouragement for the support centers to reach out to Councils on Aging as they have the knowledge and awareness of services of elders.
* Discussion on the Council on Aging doing a training at the Autism Support Center – not as a mandate but more as an encouragement
* Workshops that are currently being offered (Lea Hill sent out the information) “Autism Across the Life Span”,” Invisible Spectrum” (for older adults), and “Hoarding” workshop – these may be helpful in supporting aging parents
* The recommendation could be broader and include looking at aging parents, case management and local collaboration

3. 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.

* This is ongoing work
* Discussions around learning more about these services and supports and getting a better handle on what is currently out there – possibly having presentations on various programs and learning about their structure
* It was asked if the term “forensic” could be added to this recommendation as some providers are seeing more court involved individuals
* Ms. Kain will draft the recommendation to include this and send to the co-chairs

**Next Steps**

* The Autism Commission will meet on September 26th and these recommendations will be presented.
* At the next meeting of this subcommittee, Jay O’Brien from AANE, will present the Life Net Program
* Further discussion on case management.

The next meeting of this subcommittee will be on October 23rd, 10:00 a.m. – 12:00 p.m. at 500 Harrison Ave, Boston.