Autism Commission

Adult Sub-Committee Meeting Minutes

September 7, 2018 – 1:00 – 3:00

500 Harrison Avenue, Boston, MA 02118

Attendees: Kathy Sanders, Christine Hubbard, Todd Garvin, Beth Zwick, Josh Greenburg, Maria Stefano, Lea Hill, Janet George, Carolyn Kain, Nancy Marticio, Cynthia Berkowitz, Rita Gardner, and Kathy Stern.

The minutes from the last meeting on July 16, 2018 were reviewed and approved unanimously.

Kathy Sanders introduced Josh Greenburg as a new member of the committee: Josh is the Special Assistant to the Deputy Commissioner at DMH. Each of the other subcommittee members introduced themselves.

Kathy Sanders explained that at today’s meeting the subcommittee would be working to finalize its recommendations for the Autism Commission. Chris Hubbard clarified that while this is the adult subcommittee it did not have responsibility for healthcare, housing, or employment as those issues are being addressed by other subcommittees. Ms. Kain stated that each subcommittee was asked to submit up to three recommendations to the Autism Commission for consideration in developing its annual report and that the subcommittee recommendations would be discussed at the next Autism Commission meeting on September 27th.

Ms. Hubbard then read draft recommendation #1 for the group. Ms. Kain mentioned that this issue was raised by Ms. Jekel at the previous meeting as AANE gets call from families of adults with autism that have been isolating in their homes and need help trying to get them to engage in their communities. Ms. Kain asked Ms. Hill and Ms. Stefano to let everyone know about their pilot program that involves this issue. Ms. Hill described the proposal that she and Maria developed and that DDS was going to start a pilot program with DMH to assist a number of individuals that they have identified who have severe anxiety or OCD that prevents them from engaging in their community and to try and provide them with the clinical services needed to encourage skills and friendships. These are individuals who are not accessing services currently from DDS because of these interfering mental health issues.

Kathy Sanders said the recommendation was revised to be less prescriptive to allow for flexibility between DDS and DMH on how best to meet this need. She said there have been discussions about this type of issue at the Commissioner level. These are individuals who do not present with ID and they didn’t know yet how to best approach these issues and they were looking at the ways to conduct outreach.

Cynthia Berkowitz said that in working with adolescents DMH has seen the importance of having individuals be out in the community and in an inclusive atmosphere because issues of isolation tend to snow ball into bigger mental health issues. Beth Zwick and Chris Hubbard suggested that the recommendation be revised to also include DMH.

Ms. George stated that this was not an issue of training but more of a consultation issue and on-going support, as it is not direct training for individuals. Ms. Kain said the recommendation has been revised from its original language that was more directed at the training for individuals at the Autism Support Centers and the Family Support Centers to be able to provide parents with the type of consultation they were seeking to assist their adult children with ASD. Kathy Sanders said that the pilot program will better inform DDS and DMH how to meet this need. Cynthia stated that many at DMH do not have expertise on ASD, and that DDS’ experience in assisting these individual will support DMH’s role on how to do this family work.

There was consensus among the group to revise the recommendation to add DMH and to change training to consultation.

**Recommendation #1 of the Adult Sub-Committee:**

Families of 20 to 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. The Adult Subcommittee recommends that 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.

Chris Hubbard presented Recommendation #2 to the group. Janet George explained that EOEA has Aging Service Access Points (“ASAP”) and a screening tool is used by nurses to collect data and part of that tool includes a person being able to disclose if they have ASD. She said that it is a 35 page screening tool. Ms. George said that EOEA collects data and that we needed to understand how, if at all, that data was being used by EOEA.

Mr. Garvin asked if this recommendation would only address those with a formal ASD recommendation since many older individuals may not have a “formal” diagnosis, and it took many years before he got his diagnosis. Ms. Kain said that in working with EOEA part of the discussion needed to include if they understand ASD, how it presents in individuals to recognize it, and what it any resources did they have in place to assist individuals with ASD. Ms. Sanders said this was opening up a relationship with EOEA to serve older adults with ASD. Ms. Hubbard suggested the word investigate be changed to gather information to better reflect the collaborative nature of the recommendation.

Ms. Zwick informed the group about work being done by the Becker Fund and the ARC under Kerry Mahoney, she said that both agencies are working with older adults to create best practices and that specific case studies should come from this work to inform us how to assist adults aging with ASD.

Additional changes to language were discussed and agreed upon.

**Recommendation #2 of the Adult Sub-Committee:**

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 service are aware of the needs of individuals with ASD and receive training on how to address these needs.

Ms. Hubbard read the third draft recommendation to the subcommittee. Ms. Gardner pointed out that this recommendation was made by the previous Autism Commission in 2013, and that it involves the individuals with ASD with high acuity. Ms. Gardner talked about the high cost of supporting these individuals safely, the need for providers to do private fundraising for years, and the crisis to obtain and keep staff due to the state’s low unemployment rate. Nancy Marticio said that this is also challenging because of parents’ demands for their family members to get out into the community and to be able to do it safely.

**Recommendation #3 of the Adult Sub-Committee:**

The Adult Subcommittee recommends that 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.

Next items

The subcommittee then discussed issues that had been sent over from the Healthcare subcommittee. The first discussion was about AFC and PCA services and that the regulations regarding these types of services do not meet the needs of individuals with autism because they do not require hands on assistance.

The next discussed issue was adult foster care (AFC) and the fact that the current regulations do not allow single parents who are guardians of their adult children to be an AFC provider.

The group also discussed the need for respite, which is not a service covered by MassHealth, and that this service could prevent ED Boarding situations and also the need for residential placement.

The issue was raised about the “newly eligible” individuals with ASD only being able to access HBCS under DDS. Ms. George explained that it is not possible for individuals with **ASD only** to meet the waiver requirement for level of care. She also explained that DDS puts up 100% of the funds and gets reimbursed by the federal government and they can only bill under the waiver for individuals who meet the level of care required under the waiver. Individuals also need to have MassHealth standard and state dollars pay for individuals who don’t have MassHealth.

Chris Hubbard then presented an issue raised at the Healthcare subcommittee by a psychologist that the tools used by DDS are not appropriate to identify the deficits of individuals with Asperger’s. The group agreed that more information needed to be gathered on this issue. Mr. Garvin noted that he was not found eligible and felt that the evaluations did not target his areas of need.

The group then selected dates and times for their next meetings.

November 2, 2018 11am-1pm, 500 Harrison Ave

January 11, 2019 11am-1pm, 500 Harrison Ave

March 5, 2019 11am-1pm, 500 Harrison Ave

May 17, 2019 11am-1pm, 500 Harrison Ave

There being no further business the meeting adjourned at 2:45pm.