Autism Commission

Adult Sub-Committee Meeting Minutes

June 7, 2018 - 1:00 p.m. – 3:00 p.m.

500 Harrison Avenue, Boston, MA 02118

Attendees: Dania Jekel, Maria Stefano, Lea Hill, Kathy Sanders, Janet George, Christine Hubbard, Carolyn Kain, Dianne Lescinskas and Nancy Marticio.

The minutes were approved from the last meeting on January 26, 2018.

**New Co-Chairs of the Adult Subcommittee**

There has been a reorganization of subcommittees of the Autism Commission and Chris Hubbard and Kathy Sanders are the co-chairs of the adult subcommittee. There is an additional subcommittee, Health Care, and it will look at insurance as well as mental health issues. Members of this subcommittee asked about self-advocacy participation on this subcommittee. Ms. Kain said that Todd Garvin is a member of the commission as well as a participant of this subcommittee but due to work restraints, he has not been able to participate as often. It was asked that members continue to look for self-advocates that may be interested in this subcommittee and have them reach out to Carolyn Kain. It was also asked if anyone from HMEA would be interested in this committee and if Sue Loring could help identify someone.

Kathy Sanders discussed the restructuring of the subcommittee and reviewed the work that has already been done in the past.

**Review of Training “Understanding Autism Spectrum Disorders (ASD) for Adults and Introduction**

There have been multiple requests to provide a basic (101) ASD training for people who are direct support workers but unfamiliar with ASD. Trainings are being developed through the DDS training division and will address children, adolescents and adults for a basic understanding of ASD. The Autism Commission would like compile a list of trainings.

The draft training on Adults was provided to this subcommittee for review and comments:

* Language could be softened for people who are new to Autism and better tailored to the audience
* It’s deficit based vs. strength based
* Slide 1. – Is describing a disorder and Ms. Jekel stated it is not a description of who she works with and feels this is an ethical issue
* The slides could benefit from a definition that includes strengths of someone with ASD
* There are images of children in the presentation yet it is geared towards adults
* It was suggested to add a slide about medical and dental issues that could trigger behavior – and how most behaviors are not intentional
* It was asked if there could be a slide on tantrums vs. meltdowns
* Try to get a across the uniqueness of ASD and the wide spectrum
* Anxiety is one of the biggest issues that individuals with ASD face and it is not mentioned in the slides
* It was suggested to start off with the complexity and strengths of ASD and then come back to the solutions and incorporate strengths with solutions
* Add pacing and rocking as activities that are calming and are coping strategies
* It was suggested to add utube videos of individuals with ASD explaining who they are and their reaction to some environments – this could be the opening of the training
* Change the title? – Recognizing and Understanding ASD
* Addressing the issue of anxiety by discussing that adults with ASD are behind their peers chronologically in social issues and that they are always in an anxious state caused by the impact of ASD
* The PowerPoint should address challenges, strengths and impacts

The team will work with Valerie (DDS) to modify the PowerPoint and incorporate some of the suggestions/changes. It was asked if anyone had additional comments on this training they should send them to Ms. Kain. It was also asked if there should be a recommendation to the full commission requiring *other state agencies to be familiar with ASD*. It was said that there is a large gap in the state system of what people know and the charge of the commission is to address the gaps. Ms. Kain has done a webinar for DCF workers to address children and ASD.

**Review of prioritization of recommendations from Autism Commission members assigned to Subcommittee on Adults**

This committee reviewed the charge of the Autism Commission. Ms. Kain discussed the 2013 Autism Commission report and said it is important for the commission members to look at the report and what has been accomplished thus far and what in it should move forward. Subcommittees should look at developing new recommendations and once developed and submitted, they will be vetted by the Commission. This will help with keeping subcommittees focused on priorities. It was asked that each subcommittee develop up to three (3) recommendations and these will need to be submitted to Ms. Kain within 1 week prior to the September Commission meeting to give the members opportunity to review and discuss.

Ms. Jekel discussed putting forth a new recommendation of *DDS, DMH and MRC collaborating to communicate on issues related to ASD*. MRC and DMH have developed a relationship on Clinical Based Flexible Support. Starting July 1, 2018, DMH’s Adult Clinical Services will be integrated with ACO’s. MRC is being relegated to be the hub for the employment side. DMH will train MRC on the mental health issues. DDS already has a number of interagency agreements with MRC. Ms. Jekel further stated the recommendation to say that *any state agency dealing with adult autistic people should be under an agreement to provide better case management*. Ensure better collaboration with the 3 agencies (MRC, DMH, DDS) is the goal. Another recommendation from Ms. Jekel is to *look at the Department of Elder Affairs and people with ASD – they need more assistance as they age. A recommendation on how to develop a relationship with Elder Affairs*.

**Next Steps**

This subcommittee will focus on the purpose of the subcommittee for next year and look at our scope of work. It was asked that members read the Autism Commission Report and the recommendations related to this committee and come prepared to brainstorm to prioritize up to three (3) recommendations to be reviewed by the Autism Commission.

The next meeting will be on **July 16, 2018** and it will be held at AANE located at 51 Water Street, Watertown.

This committee will also meet on **September 7, 2018**. Ms. Stern will send out invites to the members of this subcommittee.

With no further business to discuss the meeting was adjourned at 3:00 p.m.