Autism Commission

Adult Sub-Committee Meeting Minutes

July 16, 2018 - 9:30 a.m. – 11:30 a.m.

The Asperger/Autism Network (AANE)

51 Water Street, Suite 206, Watertown, MA 02472

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

Remote Access: Kathy Sanders, Rita Gardner and Cynthia Berkowitz

It was stated that the meeting was subject to the Open Meeting Law and that the Sub-Committee 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 tele-conferencing. Remote access was approved unanimously.

The minutes from the last meeting on June 7, 2018 were reviewed and approved unanimously.

**Announcements**

Ms. Jekel discussed a focus group that AANE is hosting in the North Hampton/Springfield area with adults to figure out what newly eligible adults are looking for in terms of services, what they like and do not like, and to also do a survey to look at the services that are being used and what services they may like to see in the future. Information from the survey may help inform this subcommittee with developing recommendations. DDS has also done a focus group in that area regarding employment.

**Review, Discussion and Prioritization of Recommendations from Autism Commission Members and Other Recommendations (Adults)**

The first agenda item for this meeting, Update of Progress on Subcommittee Goals from 2017 will be blended into this discussion.

The co-chair of this subcommittee, Christine Hubbard, walked through the recommendations and followed up with a discussion on each one. It was also noted that there will be discussion of Ms. Jekel’s newer recommendations that are in the minutes from June’s meeting.

Ms. Kain reiterated to this subcommittee that they are able to put forth up to three (3) recommendations to be further reviewed by the Autism Commission and the recommendations will need to be submitted at least one (1) week prior to the Autism Commission meeting on September 27, 2018.

*Review of Recommendation on Case Management Services and Indv. Supports*

* AANE does a lot of parent support and coaching and find that parents do not know what to do when their adult child isolates themselves. AANE feels this is a big priority, supporting parents of 20-30 year old adult children.
* AANE also has an online support group and find that parents really want to talk to each other about issues regarding their adult children. They also provide 1:1 parent coaching.
* Issues arise when the adult is their own legal guardian.
* Ms. Kain discussed the Family and Autism Support Centers and asked if AANE is referring these families/adults to the centers. They do a lot of parent workshops and trainings. There should be more education on letting families know about these support centers.
* Ms. Jekel commented that there are only 7 autism centers across the state and they are underfunded. She also said that in the past these centers focused more on children and they should consider a higher focus on the 20-30 year old adults with ASD.
* Comments were made that this behavior (isolation) is not unique to ASD and that DDS will get calls to remove adults from a family’s home. It can be difficult to get some individuals to accept services.
* AANE has the expertise on how to train parents to help their adult children once they are isolating themselves in a family home. Also, MassHealth wants to explore how to better support families.
* Discussion around having targeted parent training at the Support Centers to help families of 20-30 year old adults with ASD.
* Lea Hill will rewrite the recommendation and incorporate language that was discussed at the meeting. She will send the revision to Ms. Kain for review and it will then be sent out to the subcommittee.

*Review of Recommendation of New and Creative Models of Support for Newly Eligible Aging Adults*

* There is no data on the numbers of aging adults with ASD.
* This subcommittee will reach out to Elder Affairs to gather information – ask what they know about ASD. Articulate our shared interest on this population and ask how we could also approach the Council on Aging.
* Could there be an interagency agreement similar to DDS and DMH?
* DDS eligible that end up in nursing homes is mostly a temporary situation – DDS has specialized homes for their population.
* An overarching recommendation could be to review services and needs for those with ASD across a lifespan and work with other state agencies on how to access those services from other state agencies.
* Ms. Kain reminded this subcommittee that some of the recommendations that were in the Autism Commission 2013 report were written broadly and as a result they did not have any actions taken on them by state agencies. There is a greater likelihood of progress being made if a recommendation has an action plan of what steps need to be taken.
* Health Care Proxy and Power of Attorney is an issue for some aging adults with ASD – they may not have family members to do this for them.
* Ms. Zwick discussed the issue of dementia and that there are studies being done on ASD being protective of dementia. Kaitlin Coyle, from UMass Boston, is doing research on this issue. We will collect more information on this topic prior to approaching EOEA.
* Ms. Kain will draft a recommendation and send it to the subcommittee for review.

*Review of Recommendation on DMH Reporting to the Autism Commission on the number of Indv. Found Ineligible*

* DMH is able to track if they are found eligible but their system cannot track individuals found ineligible. The individual could be found ineligible for other reasons.
* Dr. Sander said she will discuss this issue with the Deputy Commissioner at DMH.
* DDS had built in customized designed screens to capture more specific data on their computer program. Dr. George will share this information with Dr. Sanders.
* It was asked that this recommendation be crystalized and sent back out to the subcommittee to decide if it should one of the three recommendations moved forward.

*Review of Recommendation on Expanding and Developing Additional Specialty Day and Employment programs*

* Current Day-Habs and CBDS programs are not designed for individuals with ASD with high acuity.
* MassHealth could help to establish their own specialty ASD adult programs for Day-Habilitation and DDS for Community-Based Day Support.
* Ms. Kain will draft a recommendation and it will be sent out to the subcommittee for review.

There was discussion by the subcommittee on having an additional meeting, prior to the meeting on September 7th, to discuss the remaining suggested recommendations. It was decided that this subcommittee would prioritize three (3) recommendations and further discuss these at the next meeting on September 7th. Ms. Kain will draft the three suggested recommendations discussed and agreed upon by the subcommittee at this meeting (the first one with Lea Hill of DDS) and they will be sent to the chairs of this subcommittee to determine if another meeting will be necessary.

The next meeting of this subcommittee will be on September 7th at 10:00 a.m. – 12:30 p.m. and will be located at AANE.

With no further business to discuss the meeting was adjourned.