Autism Commission

Health Care Sub-Committee Meeting Minutes

August 1, 2018, 1:00p.m. – 3:00p.m.

Lurie Center – One Maguire Road, Lexington, MA

Present: Carolyn Kain, Amy Weinstock (chair), Laura Conrad (chair), Dianne Lescinskas, Christine Hubbard, Maura Sullivan, Shari King, Matt Selig, Dan Rosenn, Julie O’Brien, Kate Ginnis and Ann Neumeyer

Remote access: Jean Frazier, Bernadette Bentley and Robert Azeez

Carolyn Kain 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 by the members present.

**Introductions of Members of Subcommittee**

The chairs of the Health Care Subcommittee introduced themselves. Ms. Weinstock is the Director of the Autism Insurance Resource Center at the University of Massachusetts Medical School’s Eunice Kennedy Shriver Center and Laura Conrad is the Program Manager, Children’s Behavioral Health Initiative for MassHealth. The subcommittee members also introduced themselves and provided the members with their professional role and the interest in the work to be done as part of the Health Care subcommittee. There is an effort underway to recruit a self-advocate to participate in this subcommittee. The Healthcare subcommittee was formed due to the recognition of the need to better address the healthcare needs of individuals with ASD. Healthcare needs were being addressed in the Adult Subcommittee prior to this committee being formed.

**Discussion of Autism Commission’s Role, Subcommittee’s Role, Process for Subcommittee to make Recommendations**

Ms. Kain, Executive Director of the Autism Commission, provided this new subcommittee with information on the Autism Commission and how it was established and the work that is currently being done by the subcommittees of the Autism Commission. The most current Autism Commission Report (2017) can be found on the Commission’s website [www.mass.gov/orgs/autism-commission](http://www.mass.gov/orgs/autism-commission). There are also additional reports and the minutes from all of the subcommittee’s work on the website.

This subcommittee will need to submit up to three (3) recommendations one week in advance of the Autism Commission meeting on September 27th to be considered for submission into the annual report. The new report will be filed with the governor on or before 3/1/2019.

The work of all of the subcommittees is an ongoing process and a continuous dialogue. The work that comes out of these meetings does not have to be a formal recommendation to be able to move forward. This is an ongoing process.

**Discussion of Proposed Recommendations Related to Healthcare from Individual Commission Members**

This subcommittee will review the recommendations that were submitted by individual commission members. The plan is to have this subcommittee meet bimonthly and get a consensus of the top three recommendations ready to submit to the Autism Commission for consideration into the annual report.

 *2017 Recommendations from Individual Commission Members*

1. **Extend MassHealth Coverage of ABA, and other medically necessary treatment for persons over the age of 21.**
* This recommendation was made by several Commission members
* ARICA, the State’s private insurance mandate, has no age limit, allowing adults with coverage under ARICA to access ABA.
* ABA is used a lot less in adults but still is a critical tool
* The transition from school to the adult world can be especially problematic if ABA treatment under MassHealth ends at the same time because of the age limit.
* This is also an access issue – there are not a lot of providers with experience with adults
* ABA services over 21 is a budget issue for the state. There are no matching funds coming to the state from the federal government
* Consider the wording of the recommendation – home and community based services – skill building for employment – vocational/life skill training
* Some members expressed concern about a lack of evidence based literature to support ABA services over 21 years of age.
* It would be beneficial to word this recommendation more broadly rather than limit to just ABA, similar to language in the private insurance mandate.
* Services could be done through DDS – ISP – currently DDS doesn’t have a treatment plan or the trained staff
* There is difficulty for many that are ASD only to gain eligibility through DDS – the diagnostic tools are not appropriate for this group and many are being found ineligible because of the tool being used to diagnose– also, ASD individuals (adults) have heard there is no funding so they are not applying – there is a large effort being made to capture ASD only in the Turning 22 funding, prior to them leaving their school
* There are efforts being made by DDS to evolve and expand their services to better meet the needs of individuals with ASD – coaching services if offered by DDS
* There is discussion at DDS to create a new waiver for the newly eligible – not sure if other states have a similar waiver and waivers look very different in other states

The co-chairs and Ms. Kain will work on the language for this recommendation and it was suggested that it could say “Extended coverage of medically necessary treatment, including but not limited to ABA, for persons over the age of 21.”

Dan Rosen will email the co-chairs language for a new suggested recommendation for DDS to look at a new, more appropriate, adult diagnostic tool for individuals with ASD only. He has had conversations

with DDS regarding this issue.

1. **Health Care Provider Training**
* Carolyn Langer updated this subcommittee on [Pathways to Inclusive Health Care (PIHC),](https://shriver.umassmed.edu/programs/pathways-inclusive-health-care-pihc) <https://shriver.umassmed.edu/programs/pathways-inclusive-health-care-pihc>, an innovation gap year for post graduate students prior to attending medical school. Participants will work with providers to gain firsthand experience working with individuals with ASD and pursue a certificate program. The program, housed in the Shriver Center, is modeled after Teach for America and the first cohort of students began in August.
* Operation House Call continues its’ work of providing medical students the opportunity to learn from families and individuals about disability. Their interest and motivation grows and it helps to diminish the fears that some may have around certain behaviors
* It was asked if there training for PCP’s – is there an opportunity to provide a training certificate
* PCP for adults – Dr. Bob Baldor and Dr. Debra Dryfus are two identified practitioners that have experience working with adults
* Children’s Hospital uses SymPeds - an ASD simulation floor for families and staff to learn more about ASD in a hospital setting
* BMC has a grant to provide training – could they use the simulation model at Children’s to do the training?
* BMC has also developed their own training videos and it is being used hospital wide
* The Workforce Development subcommittee is not addressing this area but it has been covered by the Adult subcommittee
* The training recommendation should be written broadly
* This subcommittee could work on a list of what already exists currently for training
* MCPAP for ASD was discussed – how could MCPAP expand to address the needs of ASD adults
* Tele-teaching was a model of training that was discussed – it is a team approach including the parent, psychiatrist and social worker
* ECHO – Extension in Community Health Outcomes – an evidence based model
* Is there an inventory of best practices all in one place for people to access?

The co-chairs and Ms. Kain will work on the language for this recommendation. It was suggested that it could include, training, not just for medical personal, but also dental and visual. Also, to include training for all individuals that may come in contact with patients in a hospital setting.

1. **Expand Mental Health emergency and treatment services to specifically address the needs of children and adults on the spectrum.**
* There was discussion on Emergency Room boarding of ASD individuals – there is a lack of appropriate placements so they are getting stuck in the ER – ASD individuals are at risk for longer boarding
* Most healthcare workers are not well trained to work with ASD individuals
* The Mobile Crisis Unit from DMH was discussed
* Children’s Hospital has a mental health campaign and a grant looking at this issue – they are looking at the development of specialty services for ASD and are working on a White Paper to be completed by years end. It is reviewing policies and recommendations for legislative changes specific to this topic
* The timing of this recommendation is critical and it is ripe to address it now
* The recommendation could include the formation of a diversion program, more training and more options for families and individuals that are appropriate and include specialized treatment.

Ms. Kain and the co-chairs will work on the language for this recommendation.

1. **Revise MassHealth Care regulations to broaden Adult Foster Care and Personal Care Assistant (PCA) services to better meet the needs of individuals with autism.**
* Single parent language did not change and this is an equity issue for single parent
* A legal guardian cannot be an AFC but in some other states it is allowed
* Maura Sullivan from the ARC will be able to update this subcommittee on the work being done on this bill

It was noted that recommendations number 4, 5 and 6 need more research prior to this subcommittee submitting them for consideration for formal approval. It was also discussed that these recommendations may be more appropriate for the Adult Subcommittee and Ms. Kain will discuss this with the Adult subcommittee chairs. Ms. Weinstock also discussed the last few recommendations under Insurance Coverage. Those discussions will be tabled for now.

**General Discussion**

The Adult Subcommittee is working on Mental Health and Emergency Departments issues. There is a facility that will be opening in Westborough but it is not staffed yet.

Dan Rosenn discussed the need for a clearing house of resources. He receives 5-10 calls per week from individuals looking for all types of resources but many are looking for specific physicians to help with healthcare needs as it relates to ASD. Some resources that were mentioned include: Autism Support Centers, THRIVE directory, Autism Commission brochures and website. Social Media was discussed as a good tool and many young moms are using this and creating groups.

There was discussion on having nurse practitioners, who have extensive training, to sign off on an ASD diagnosis. It is a large obstacle in getting a diagnosis in a timely manner and will require a statutory change. This may warrant further discussion with MassHealth. It was also noted that the scales (tool) used for children are not workable for adults.

There was discussion on SSI and that is designed more for people with physical disabilities. The subcommittee agreed to revisit this issue.

**Next Steps**

This committee identified the first three recommendations to consider for submission for the next annual report. Ms. Kain and the chairs of this subcommittee will work on the language of the recommendations and Ms. Kain will distribute to the subcommittee members. This subcommittee will meet bimonthly and a doodle poll will go out to members to find a date that works best for most members.

With no further business to discuss the meeting was adjourned.