Autism Commission

Health Care Sub-Committee Meeting Minutes

February 27, 2019, 12:00 p.m. – 2:00 p.m.

Lurie Center – One Maguire Road, Lexington, MA

Present: Carolyn Kain, Amy Weinstock (chair), Laura Conrad (chair), Dianne Lescinskas, Christine Hubbard, Maura Sullivan, Julie O’Brien, Kate Ginnis, Shari King, Nancy Allen, Elise Ressa and Ann Neumeyer

Remote access: Carolyn Langer, Robert Azeez, Bernadette Bently, and Matt Selig

Ms. 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.

**Review of Meeting Minutes from October 23, 2018**

The minutes from the Health Care Subcommittee, on October 23, 2018, were reviewed and approved unanimously.

**Update on Subcommittee Priorities**

This subcommittee reviewed the three priorities from the Autism Commission report.

1. *Extension of MassHealth coverage for persons over the age of 21*
* There has been legislation filed regarding this issue
* The Arc has prioritized a bill to improve coverage for adults but the language does not include ASD
* Ms. Weinstock will take the lead on this issue
1. *Expansion of training on ASD*
* The goal for this priority is for members to come up with an action plan. Ms. Weinstock will develop “next steps”
* This dovetails with today’s presentation from the Children’s Mental health Campaign
1. *Expand Mental health emergency and treatment services*
* This priority is the focus of today’s meeting

**Presentation on Behavioral Health Urgent Care Project – Kate Ginnis, Elise Ressa**

The Children’s Mental Health Campaign is doing research to develop an effective model of urgent care for children and adolescents experiences a behavioral health crisis. They are specifically addressing what elements of a model are important to meet the needs of youth with ASD and or I/DD, and how models may need to be adapted, changed, or nuanced to meet these needs. They are looking for feedback from the subcommittee.

* The CMHC Executive Committee consists of 6 partner organizations:

MA. Society for the Prevention of Cruelty to Children, Boston Children’s Hospital, Parent/Professional Advocacy League, Health Care for All, Health Law Advocates, MA Association for Mental Health.

* Boarding Study revealed – during a 12 weeks (1 week per month) of 2016 – 1,028 youth boarded – 87% of youth with ASD or I/DD boarded and 38% of who boarded for 3 days or more.
* Ms. Kain commented that the delivery system has not kept pace with the current need. We should focus on how they got to the ER and address the crisis in the community
* Slide 5 demonstrates the current system and how all roads lead to the ER – this project is meant to address how to make it better for families.
* Slide 6 defines Behavioral Health Definition (created in this work) – *In contrast to a psychiatric emergency, urgent behavioral health care – inclusive of mental health, substance abuse, and/or co-occurring conditions-responds to needs that fall short of posing an immediate risk of harm to self or others. Urgent care needs are revealed by changes in behavior or thinking, role dysfunction, emerging intent of self-injury, or threats to others.*
* Findings to date include – lack of continuity of care, urgent care centers do not treat behavioral health conditions, few options for CSU beds for children and adolescents in need of 24 hour or longer stay, long waits for outpatient care (refer to slide 7 of presentation)
* Characterizing an urgent need – rule out underlying medical reason for behavior (first step in the process), communication and the ability to communicate needs, presentation prior to going to the ER and how has that changed – medical issues and a nonverbal individual can look like mental health issue.
* Ms. Sullivan commented models should also have a dental component. She also commented that it is important to work with your own medical team first (could involve lab testing, x-rays), and if they cannot figure it out, to then go to the ER.
* Ms. Kain discussed school and the IEP – are the supports needed in place during the school day – parents do not always know how to advocate for those services
* Some Best Practices were discussed – Autism teams in hospitals, ABA and not tutoring, training of all hospital personal, modify environment to make it less traumatizing, quiet rooms, do not put a wristband on the patient, training on how to work well with the parents, more efficient “check in” with immediate access to a room
* Ms. Weinstock talked about Cambridge Hospital – they have a psychiatric emergency room so they are better equipped to handle patients with ASD
* Ms. King said Children’s Hospital in Philadelphia has a good model – separate wing with a Behavioral Health Unit – 6 beds within the ER
* Tufts has sensory friendly rooms – smaller space with equipment out of site, dimed lights and subtle colors. Newton Wellesley Hospital will meet you at the door if you have someone in a crisis.
* There was a question regarding settings – a place where families can go prior to going to the ER – possibly a Community Health Center
* Slide 12 discusses a Behavioral Health Urgent Care Model – this model will not be situated in any single state department but will be integrated into the health care system – figuring the pattern of behavior that will eventually escalate - a place that you can go when you recognize that a crisis is on the way. Envisioning a crisis provider that could come up with a crisis plan. A case manager for families could be helpful
* Connecting people to resources should start at the time of diagnosis
* All hospitals should be able to do best practices for ASD – at least at a basic level and then there should be more specialized care – similar to a school system
* MCPAP – look at that model – ABA consultant
* Mobile Crisis Unit – modified or enhanced expertise of ASD – training on ASD
* Dr. Langer discussed tele-health with access to a psychiatrist, BCBA and additional resources – Continuum of Care should be addressed.
* There was a discussion on workforce issue and ABA – this is connected to ED boarding – The ARC has prioritized the workforce issue this year and is working to get rates up to $17 per hour. Loan forgiveness is also being addressed.
* Further discussion on schools and families – lack of knowledge and rights – they are unable to access services and some are underserved by their school districts. Families need support on navigating the school system – if these families are more supported it could help with the ED boarding issue.
* DDS/DESE Program – 4 million increase ask in the budget

Elise asked this group to email any additional comments.

With no further business to discuss, the meeting was adjourned.