

**Commonwealth of Massachusetts**

**Executive Office of Health and Human Services**

**Updates from the**

**Autism Commission’s**

**Subcommittee Co-Chairs**

### May 30, 2019

## Co-Chairs Dr. Russell Johnston and Michele Brait

**Recommendation #1 Providing actionable feedback to the Massachusetts Department of Elementary and Secondary Education (DESE) on the IEP Improvement Project specific to the needs of children with Autism Spectrum Disorder (ASD)**

The 0-14 Subcommittee has developed a set of recommendations for DESE on the IEP Improvement Project in order to ensure that the IEP process focuses on key topics related to ASD. Specifically, the recommendations focus on key areas such as the seven specific IEP considerations for students with ASD, creating effective functional behavior assessments and behavior intervention

plans and addressing student-specific communication needs through the use of aided and augmentative communication. The recommendations also focus on issues related to families of children with ASD, including targeted areas in which their feedback can be obtained prior to IEP meetings, and specific ways in which the cultural and linguistic assets of families can be considered through the IEP process. The 0-14 Subcommittee is pleased to share their

recommendations with DESE and they anticipate seeing how their input is reflected in the forthcoming

changes introduced by the state education agency.

**Recommendation #2 Improving recruitment and retention strategies of Board Certified Behavior Analysts (BCBA) and related behavior therapists in public education settings**

The 0-14 Subcommittee determined that a key area of influence for their collective effort would be on sharing promising practices for recruiting and retaining BCBAs and related behavior therapists in public education settings. Through their collective knowledge, the subcommittee noted that public school districts struggle to hire and maintain staff who are effective at meeting the needs of children with ASD. They also identified isolated instances in which districts have developed effective recruitment and retention strategies, and the subcommittee expressed its interest in expanding the practices more broadly across the commonwealth. In order to better understand and expand these positive practices, the subcommittee has developed two surveys (one for special education directors and one for BCBAs) that will be sent out later this spring. The surveys ask respondents to provide information on the current practices being used to hire and maintain qualified staff in public settings. In July, the subcommittee will analyze the results and develop a draft set of promising recruitment and retention practices to be shared with school and district leaders.

### Recommendation #3 Determining how wait times for diagnosis of children ages 0-3 can be reduced so that early intervening strategies for children with ASD can be implemented as early as possible

The 0-14 Subcommittee has identified the wait times for diagnosis of children ages 0-3 as a key issue for their involvement. During the past six months, the subcommittee has gathered information on the specific nature of this issue (i.e., the length of wait times across the commonwealth) and potential obstacles for addressing this issue. During the remainder of this year, the subcommittee will continue to investigate this issue and potential solutions.

Co-Chairs Toni Wolf and Judith Ursitti

* Work, Inc. presented regarding their Meaningful Jobs Initiative.
* MRC provided updates on the status of the rollout of their new RFR.
* Subcommittee finalized training tool for DDS staff.
* Self-advocate, Greg Rosen, presented on autism advantage in the workplace.
* Jeanne Hoerter presented results from AANE Survey on Adult Services.
* Subcommittee working on survey questions for providers of Pre- ETS services. This survey will help the subcommittee obtain a better understanding of what the individuals, who work directly with the ASD population, are seeing in the field and guide us on creating a training that is to be developed by the Federal of Children with Special Healthcare Needs.
* Co-Chairs visited the Dell/EMC Autism Advantage Program.
* Subcommittee reviewing the issue of after school opportunities for students with ASD. (i.e., reviewing the need for a longer school day instead of jumping immediately to a residential placement.)

## Co-Chairs Dr. Kathy Sanders and Christine Hubbard

### Recommendation #5 Pilot program with DDS and DMH for young adults with ASD who are self-isolating

Eight individuals are participating – 5 male and 3 female, with ages ranging from 20’s to late 40’s, from the Northeast and Metro DDS regions, none of whom otherwise have funding through DDS. Many of suffer from severe anxiety and have been isolated for a long time but they express wanting to get out into the community.

Two provider agencies work with the individuals, who have 10 hours per week of support. The providers report that they do engage with the families and they are helping individuals to connect with other resources and get out in the community – employment goals are not a focus but could be later in time – some individuals are only responding through text but that is a big improvement for them

# Recommendation #6 Gathering information from

**EOEA on Adults aging with ASD**

The subcommittee received a presentation regarding Executive Office of Elder Affairs (EOEA) services, followed by discussion of issues for aging caregivers of people with autism and autistic people who are aging. Amanda Bernardo, Acting Chief of Staff for EOEA, described the variety of programs and array of services offered by EOEA. Handouts included a Fact Sheet from the Aging Services Network and a Mass Options information card.

There also was discussion about Mass Health's current efforts in looking at better training for LTSS providers around ASD and helping to connect people with ASD to the appropriate resources.

# Recommendation #7: Developing specialty ASD adult services designed and staffed to meet the needs of adults with ASD who present with severe challenging behaviors.

## It was noted that it is a challenge to establish a cost on specialty services given the lack of information about the need and the size of the population. The subcommittee discussed looking at the model at Bridgewell as a building block for this recommendation. Nancy Marticio, a subcommittee member who works at Bridgewell, reported that Bridgewell has 2 programs working primarily with young adults (ages 22-28, one 40 year old) with ASD and ID with variable cognitive impairment, serving 110 individuals.

Co-Chairs Laura Conrad and Amy Weinstock

The health care committee met with the Children’s Mental Health Campaign to discuss research they are doing to develop an effective model of urgent care for children and adolescents experiences a behavioral health crisis, 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. The committee is continuing to discuss the 3 priorities of the Healthcare committee. In addition, it is our understanding MassHealth is reviewing the recommendation to provide ABA services to members 21-26.

Co-Chairs Bronia Clifton and Dan Burke

### Recommendation #11 Design Guidelines

Working with DHCD, DDS and committee members to develop Design Guidelines for housing that will be Supportive of people on the Autism Spectrum. During this time, DHCD has presented design features

and ideas involved in two projects that are being funded by DHCD. Committee discussed key items that would be essential in design in multi-unit construction and individual dwellings. The committee also discussed the process by which DHCD could adopt guidelines, how the process would move forward and how to go about getting guidelines adopted by DHCD and DDS. Committee will also seek to get input from school based programs that specialize in supporting those on the spectrum, for guidelines they use in building homes.

### Recommendation #12 Data collection on Homeless

The committee has begun to identify who to contact and how to track autism spectrum numbers in the homeless population. The committee agreed that we need to develop the ability to use the current means of census taking in the homeless population and the ability of the providers in serving this population. Committee outreach has include with organizations such as the Pine Street Inn, Bridge Over Troubled Waters and Health Care for the Homeless. The committee will seek to reach out to agencies such as HUD and the Statewide Point in Time survey of homeless to see if their surveys can be modified to reflect questions to try and better identify the number of people on the autism spectrum in the homeless population.

**Recommendation #13 Data collection at Hogan Unit**

The committee worked with DDS on collecting data on the number of individuals who have been admitted to the Emergency Stabilization Unit at Hogan/Berry from group residences. The 2018 Commission report identified one of the areas of this goal would be for DDS to collect data if possible whether any services or supports could have prevented any admissions. During our discussion, it was clear that due to the variable nature of admissions, this type of data collection is not possible. However, the committee agreed to modify the goal to reflect asking DDS to track data regarding the “length of stay” that people are in the Unit and then try to follow up as to reasons why certain individuals are there for long periods of time, which is the overall concern.