**Autism Commission, Birth to Fourteen Years Old**

**Subcommittee Meeting**

January 9, 2019 10:00 am-12:00 pm

One Ashburton Place, Boston, MA

Present: Co Chairs Russell Johnston and Michele Brait, Joan Rafferty, Zachary Houston, Shari King, Julia Landau, Carolyn Kain, Dianne Lescinskas.

Members participating by phone: Michele Poulin, Alexis Glickman, Diana Perry.

Russell Johnston called the meeting to order and welcomed all members of the Birth to Fourteen Years Old sub committee meeting. Dr. Johnston noted that the meeting was subject to Massachusetts Open Meeting Law, and present members needed to vote to allow non-present members to participate via telephone. Subcommittee members physically present voted unanimously to allow remote participation.

Dr. Johnston read the agenda and meeting norms. The minutes from the December 13, 2018 meeting were reviewed and with one minor change, were approved.

**General Suggestions for New Electronic IEP**

Members present and on the phone were asked to provide their thoughts and suggestions to be considered for making recommendations to DESE for the new electronic IEP. While initially the committee was to make a list of general and then ASD specific suggestions, it was discussed and decided that due to overlap, we would combine them to one list. The responses Included the following:

* detailed decision making points and options for appropriate ESY placement
* flag to address listing repeated goals year to year
* electronic parent consent option for testing and the IEP
* transition information on TPF reflected in specific goals in the IEP
* prompt for transition assessments
* bullying prevention specifics reflected in goals in the IEP
* seven areas of consideration related to ASD to be more fully addressed earlier in the document
* sex education prompt for those with ASD
* yearly revisiting the decision and explain to families the impact of choosing the ALT or MCAS
* listing ASD on the IEP even if it is not the primary diagnosis of the student
* need for Home Based services for generalization to be discussed outside of family insurance benefits
* prompt for consultation component for classroom teachers in both general education and substantially separate classrooms
* ongoing SLP support for AAC including whole team, family training
* plan in place for low tech substitute when high tech ACC unavailable
* paraprofessional training
* prompt for volunteer or internship opportunities for transition age
* prompt for social skill/work soft skills
* individualization for ESY with more prompts and focus questions

Ms. Landau asked about the possibility for the subcommittee to have input on the “How to” address issues that are recommended. Mr. Russell indicated the IEP guide was in the process of being created, which would have more details.

The above suggestions will be reviewed by Ms. Kain, Ms. Lescinskas, and Ms. Brait, who will work together to draft specific questions for DESE by our next meeting in March.

**EI Wait time for Evaluation and Diagnosis**

Ms. Rafferty gave the subcommittee an update on her research in Early Intervention.

* Currently, about 450 children statewide are on wait lists for evaluation
* About 4 out of 6 children referred by EI get an Autism diagnosis
* In western MA , there are not local providers giving these evaluations, Bay State Medical has a long wait list. Some MD’s want the families to be seen at the larger developmental clinics or hospitals, instead of a psychologist.
* Some insurances require certain tests be used to rule out other conditions, so families are waiting for a workup by an MD.
* Level 2 projects with Boston EI collaborating with UMASS to get children evaluated within two months. Two screening tools are utilized and if a child gets flagged on both, they get a referral within 6 weeks. Then can do 2 evaluations in the time it typically takes for one.
* AMEGO and Children Making Strides participated in a pilot as well
* The hope is that these successful models can be shared and incorporated statewide
* Getting accurate data is difficult, as some children get services outside of EI, or through insurance, so documented numbers are low.

Ms. Landau questioned if a change in statute could be explored, to expand who can give a diagnosis. Ms. Kain indicated it was previously explored in the Birth –Three subcommittee and it would be challenging, it will impact state Medicaid plan. Ms. Landau asked that the issue be further looked into.

Mr. Houston asked if the wait list was growing or staying the same. Ms. Rafferty indicated that was not tracked, most often children come to EI due to developmental delay, then gets tested and diagnosed.

Mr. Johnston indicated there are two issues to address. The first, is advocating action around promising screening and diagnosis processes and practices. The second is around potential legislation, and if it could be pursued further.

Ms. Kain stated the Healthcare subcommittee may be looking at the medical side of these things. Ms. King asked if Amy Weinstock or Lara Conrad could present us with some more detailed information about MassHealth and Insurance issues to guide us in forming our recommendations and goals. Mr. Johnston indicated we will follow up on that issue.

**BCBA Survey**

The subcommittee discussed the goals for the survey draft questions.

* The objective of the survey is to produce a document that shows ideas that districts may not be considering for recruitment and retention of ABA staff
* Additional consideration is what culture or climate or treatment of the behaviorists may be impacting why it is difficult to recruit/retain aba staff
* Feedback Mr. Houston gained from BCBA’s included isolation of BCBA, lack of understanding of their support levels for those with ASD, treatment by others within the school system
* We would like to share what is working for districts who are successful
* What is driving the BCBA’s choices of where to work
* Do schools systems with ties to Higher Ed programs have more success
* Surveys are directed at school based settings

Two surveys, one for the district and one for BCBA’s will be drafted. Subcommittee members were asked to submit feedback and suggestions directly to Ms. Kain to incorporate into our draft survey for further review.

With no additional information to discuss, the meeting was adjourned. Our next meeting will be scheduled for March.