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

**Subcommittee Meeting**

July 17, 2019 10:00am-12:00pm

25 Kingston St. Boston, MA

Present: Co-chairs Russell Johnston and Michele Brait, Joan Rafferty Butterfield, Alexa Glikman, Michelle Jenkins, Julia Landau, Dianne Lescinskas, Carolyn Kain.

Participating by phone: Zackary Houston, Alan Jacobson, Ivys Fernandez-Pastrana.

Dr. Russell Johnston called the meeting to order and welcomed all members of the Birth to Fourteen Years Old subcommittee meeting. Dr. Johnston noted that the meeting was subject to the 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.

The subcommittee members present voted to approve the May meeting minutes unanimously.

**Reducing Wait Times for Evaluation and Diagnosis of ASD**

Joan Rafferty Butterfield gave the subcommittee an update on a few pilot programs that are ongoing in the state and focused on addressing the wait time for EI children to get evaluations and diagnosis for Autism.

* An Early Intervention survey of sixty centers with fifteen providers indicated that the biggest concern is the length of the waitlist for diagnosis. Currently there are 450 children under the age of 3 waiting.
* A developmental pediatrician at UMMC is using a level 2 test with great data for reliability, called the Rapid Interactive Test for Autism in Toddlers. If a child gets flagged on this screening, it helps direct the next step for evaluation, which would be separate for those suspected of ASD vs DD. The test looks at social interaction as part of it, and children with DD would not flag on it.
* Advantages of this test include: it takes only 3 hours of training to be able to administer, the test can be done and scored in 10 minutes, and the cost is $60 per kit and $75 if shipped. It also has very little language in it, and it has been done with interpreters, so language is not a barrier.
* EI participants can be diagnosed in about half the time as someone not already getting services.
* The training for the tool is currently being provided at no charge, which is more viable for EI staff.
* A pilot began in Worcester, where clinicians were trained in MCHAT and the Rapid Interactive Test for Autism in Toddlers. Certain evaluation slots were being reserved for children that were flagged on both the MCHAT and this tool to be seen within 6 weeks to determine Autism diagnosis.
* This was replicated in the South East region and the North East region. Currently, 85 EI staff members have been trained.
* Clinicians were also invited, in hopes of getting buy in on their part, to allocate a number of slots for evaluations of those who have flagged on the level 2 screening. These families would already have a relationship with EI and be somewhat prepared for the possibility of an Autism diagnosis.
* DPH and UMMC sent out a recruitment letter for clinicians to try to get them to partner with them and utilize this model.
* Barriers to the project include hospital/physician partner -based affiliations, and insurance- based criteria
* The goal of this is state wide implementation, getting diagnosticians to work with EI, and agree to set up slots for those who flagged on the level 2 screening to be seen for full evaluation on expedited schedule.
* Based on the data to date, 5 or 6 children out of 8 that went through the process came out with an autism diagnosis after full workup.
* Info is on Mass Act Early website and UMMC school website.
* There was discussion around how our subcommittee could assist with this project. Suggestions included sharing this information with the Health Care Subcommittee and the full Autism Commission, doing a webinar, trying to work with Mass Health to consider having a mandate for the screening, and getting the Division of Insurance involved.

Ms. Rafferty Butterfield then shared information about an RFR for getting more EI home based providers. There are currently 15. They received 46 responses and got some feedback that was helpful and somewhat related to one of our other priorities, addressing the shortage of ABA providers in the state.

* Long wait lists for after school hours was a common theme
* The 5 top offers to recruit/retain included: career track opportunities such as RTB training, having a dedicated team, competitive wages and incentives, formal collaboration with higher education and mentorship, work /life balance.
* When asked how DPH should assess applicants, the top answers were child development knowledge, structure for recruitment, billing, infrastructure, data about personnel (RBT issues, staff turnover)
* With respect to BCBA guidelines regarding caseloads, feedback indicated that a minimum caseload requirement may impact quality of staff and services. Also, geography can play a role in caseloads.

Ms. Landau inquired about whether or not the RFR would include issues around multilingual staff, cultural competency, under privileged areas. She added that many mass health providers cannot speak other languages so families cannot even get on a wait list. Is there a language access plan and could they be checked for a procurement team?

**Surveys for BCBAs and District Special Education Administrators**

Dr. Johnston discussed the survey generated to address the ABA provider shortage across the state. The survey that the subcommittee sent out to BCBA’s and Districts resulted in 250 responses. It is possible that there were duplications in some districts. Based on the feedback, there is a potential for a quick resource guide for District Leaders, to review what some district areas have done that was helpful in recruiting and retaining staff in public school settings. He suggested we look at what stands out in the survey responses to determine next steps.

On the BCBA surveys, the following items were noteworthy:

* Large caseload – 30 or more students resulted in some providers leaving their job feeling the number of cases was too big to manage or unethical. BCBA guideline is 15 families.
* The number of FBAs done was low for the number of caseloads. Ethically, there should be an FBA for every support plan, at least one per case per year.
* Some left positions because they didn’t feel the district was appropriately handling behavior situations because they are not having a BCBA involved in PBS decision making.
* Lack of value of BCBA in a district was an issue.
* Feelings of isolation/lack of peer group was a factor.
* Failure to provide professional development for BCBA and staff was a big concern
* Underutilization of the BCBA by districts due to unfamiliarity with the skill sets of a BCBA.
* Lack of support for training of RBTs by BCBAs was mentioned.
* Parent training/Home Services challenges due to lack of providers for after school hours.
* Division of time typically being one third administrative, one third supervising, one third direct services, which doesn’t allow for much time to share expertise.
* Evaluations for performance of direct support staff are done by DESE licensed staff, and not the BCBA.
* Desire to have collaboration, positive outcomes and concern for students were reasons for remaining in a position.

On the District Administrator surveys, the following items were noteworthy:

* Recruiting was done through an ABA international job website.
* Retention was related to pay scale, value being voiced.
* 43% of BCBAs stayed in their role for less than 3 years.

Additional comments from the subcommittee for consideration included:

* Whether an individual contract vs. union bargaining position was a factor.
* The culture of wanting to be a part of a community, but being seen as an outsider.
* Coming into a school environment with unknown expectations of you.
* Could a peer to peer observation program be an option to elevate exposure?
* There are racial equity issues.
* Could districts be better educated about what is reasonable, appropriate and expected

for ABA, to promote success in the Least Restrictive Environment?

* Are there any ABA guidelines that may be barriers for inclusion?
* Making sure there are inclusive opportunities for students in ABA substantially separate classrooms.

**DESE Memo Feedback on the new IEP Project**

Dr. Johnston provided verbal feedback from the memo sent to DESE from this subcommittee regarding the new IEP project. Many of the suggestions that were submitting in the memo are already in the works. Others are being considered. The memo was helping to DESE in incorporating information for the RFR. Documents to be updated will include a Special Education Guide, the IEP itself, a Process Guide for writing an IEP, an annotated agenda for parents, and a Parent Guide to Special Education. The suggestions in the memo may be incorporated into these other new documents as well. We will get further updates as the project progresses.

**Subcommittee Priorities Going Forward**

Dr. Johnston asked about determining our subcommittee priorities going forward. Ms. Kain indicated that any new priorities would need to be submitted to her by early September, in preparation for the Autism Commission Meeting. It was decided that we would review the original list of suggestions made by the subcommittee last year, to see if we would like to use any of those as priorities for this year. That list will be sent out to the group from Ms. Kain, and individuals can reply to her with feedback to share with the co -chairs before our next subcommittee meeting. Ms. Landau suggested we also look at our purpose as a subcommittee to help decide and to include things that no one else is looking at or where there may be gaps that require legislative recommendations. Members agreed to an August subcommittee meeting to review and vote on potential priorities for this group for the next year.

The next few meeting dates were determined, September 6th at 10 am November 22nd at 10 am and January 31 at 10 am, all at 500 Harrison Avenue. With no further business to discuss, the meeting was dismissed at 10:15am.