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

**Subcommittee Meeting**

January 31,2020 10:00am-12:00pm

500 Harrison Ave. Boston, MA

Present: Co-chairs Russell Johnston and Michele Brait, Joan Rafferty Butterfield, Michelle Poulin, Rob Polsinelli, Sarah Richmann, Shari King, Zac Houston, Julia Landau, Dianne Lescinskas, Carolyn Kain.

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. There were not any remote participants for this meeting. The subcommittee members present voted to approve the November meeting minutes unanimously.

**UPDATES ON SUBCOMMITTEE PRIORITIES**

1. **Access to Augmentative /Alternative Communication Devices**

Ms. Kain updated the subcommittee on the request for data from MassHealth on the use of dedicated and non-dedicated AAC devices for children with ASD. Under the Omnibus Law, MassHealth is obligated to provide these devices. Ms. Kain has sent a request for data to MassHealth and is awaiting a response, and will hopefully include the information in the Autism Commission Report. She plans to ask MassHealth for a breakdown of date by race and demographics on the go forward.

There was a discussion on barriers to access of the devices which include:

* Race and language barriers
* Lack of knowledge across providers
* Learning curve of devices that require training
* Need for fluency for student and all providers to make progress
* Having plan b for broken, lost, forgotten device
* Ability to utilize device both in school and at home
* Misconceptions around whether school or MassHealth should provide devices
* Family fear of ongoing reliance on it as replacement of verbal communication

The subcommittee gave feedback on potential next steps once we have the data, possibly in the form of an information campaign or DESE advisory to educate and assist schools and families. DESE is already working on this in school monitoring, checking to see that staff and parents are trained, equipment is maintained, and IEP reviews are don to check for compliance within districts. By obtaining MassHealth data, we may be able to look closer at the current implementation of providing devices, how MassHealth can further help families in this regard, and the potential for utilizing the IEP process to help with the race and language barriers issues for obtaining devices.

**Level of inclusion (full/partial/sub sep) numbers for students with ASD**

Dr. Johnston indicated that DESE can get tabulated statewide data on this subject, and wanted to hear from the subcommittee about the specific information we would like to request. Suggestions included:

* Numbers at each level for ASD students compared to those with all disabilities
* Level of inclusion for students by race and language spoken in the home
* Level of inclusion by age and how /when the students are included in mainstream
* Primary vs. secondary diagnosis of students in each level of inclusion
* Outcome for students at each level of inclusion
* Dropout rates for each level of inclusion
* Data pertaining to both day and residential schools

Dr. Johnston will bring our request to DESE and report back to the subcommittee.

**Children with ASD in DCF Care**

Ms. Kain updated the subcommittee on her discussions with DCF. Challenges include the large number of DCF staff that would need to be trained, staff turnover rates and union issue that would all have to be considered, along with the varying profile and needs that are individual to each child. DCF suggested that DDS area offices collaborate with DCF on case specific training and issues. Ms. Kain said she would reach out to try to get a DCF representative to attend a subcommittee meeting for further discussion around assisting those with ASD who are involved with DCF. Obtaining data from DCF about the number of children in DCF custody and care, as well as some outcome information for those who were in DCF care may be springboard for further recommendations.

**Collection of Data regarding Age of ASD diagnosis broken down by race**

Ms. Kain addressed the request for solutions to obtain data broken down by race and age of diagnosis. She indicated we could explore what data is available from Mass Health and the Department of Public Health, what is current, and what they have the ability to collect for us. Ms. Rafferty Butterfield shared that she has requested data for children in Early Intervention, broken down by age of diagnosis, region and primary language. Some considerations are that the data is not updated until there is a review in the current data system. The data is only on those enrolled in Early Intervention, and it doesn’t reflect the age of onset of symptoms. Most children in EI begin services without a diagnosis. She will inquire about whether she could share that data with the subcommittee. It is uncertain if Mass Health separates out data on children in EI and not in EI receiving services. Ms. Kain will follow up with Mass Health. Once we know what is available for review, we can determine next steps.

**The new Electronic IEP**

Dr. Johnston gave an update on the new DESE electronic IEP project. The document, “Is Special Education the Right Service?” is in rough draft. It will be the first piece of the process rolled out. It will contain regulatory requirements for performing evaluations, tips for districts on the system level and for practitioner tools for testing based on suspected disability. It will be going out for stakeholder feedback in February and should be fully developed in the coming months. The 13 disability categories will be defined, and DESE would like the Autism Commission’s involvement regarding Autism. He would also like our subcommittee to look at the regulations document for feedback to help with clarity in guidance. Additionally, as a subcommittee, it was suggested we look at the changes in effective progress in the flow chart, and the medical vs. the educational diagnosis of ASD. A process guide will be developed next, and DESE will be seeking assistance in the technical writing around the IEP.

**Addressing the shortage of ABA providers Statewide**

Dr. Johnston resumed our discussion from our last meeting related to exploring potential solutions for recruiting and retaining BCBA’s statewide. The subcommittee reviewed the suggested solutions list from the November minutes, and focused on four potential issues to explore further.

1. Licensure /Contracts similar to teachers with union access
2. Leveraging federal grants to districts for school improvement to manage caseloads
3. Clarification around BCBA vs. Behavior Specialist and their roles in schools
4. Global Practice Guidance for ABA specialists, within a tiered system

Dr. Johnston reported that the suggestion of providing DESE licensure for BCBA’s would be very challenging to obtain, as BCBA’s already have a credentialing body. Ms. Kain stated she believes that BCBA’s should be licensed by DESE, and the need for them in the schools has increased over time.

Mr. Huston mentioned that the license process for BCBA’s does not evaluate whether the individual is qualified to work in the school system. One can be a BCBA but not eligible for Mass License, it depends on whether a 6 core sequence or a Masters level was completed. Some BCBA’s work for agencies with a supervising LABA, but they cannot bill Medicaid unless there is an LABA.

Ms. King mentioned that BCBA’s play a role in both education and safety for students, and wondered how qualified schools were to determine if the BCBA was appropriate for the school.

With regard to leveraging grants, Dr. Johnston advised that for some districts, there is a holdback of 2-4% of some federal funding to be used on school improvements. In March DESE will be looking for some early adopter districts to look at existing services, and what they need to do with an eye on inclusion. Through professional development and changes reflected in the IEP, issues of caseloads for BCBA’s could possibly be addressed.

Regarding Clarification of ABA staff title and roles, DESE will have some new regulations coming out, could they include terminology to assist with this issue?

Related to Global Practice Guidance, Mr.Huston suggested clear guidance around clarifying to districts what the role of the BCBA is in the system and what to expect from them. If both DESE and the Autism Commission could work together and get behind it, then BCBA’s could take it to the school districts. Guidance documents already exist for BCBA licensing, so those documents would need to be looked at and considered. Dr. Johnston stated he would need to find out if DESE would be willing to put their name on something like that. Mr. Huston offered to get collogues input at an urban BCBA conference in May, and possibly some willing to work with us on creating guidance documents.

A motion was made and voted on by the subcommittee to pursue BCBA guidance for School Districts.

With no further items on the agenda, the meeting was concluded at 11: 45 am.