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

**Subcommittee Meeting**

September 6, 2019 10:00am-12:00pm

500 Harrison Ave. Boston, MA

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

Participating by phone: Beth Jerskey

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 July meeting minutes unanimously. The meeting norms were read out loud.

Dr. Johnston stated the focus of the meeting was to review prior recommendations of the subcommittee, and explore new potential recommendations for the sub-committee, with a look toward “What problem are we trying to solve?” There was some discussion about priorities vs recommendations as well as what needs to be presented at the upcoming September full Autism Commission meeting. Ms. Kain indicated that at the upcoming meeting, each subcommittee will provide an update on their previous recommendations, what work has been completed, what is still ongoing, and what if any new recommendations are being put forth for the subcommittee for the next year. She also indicated that subcommittees could work on issues or priorities that they felt were important, that were not considered to be recommendations. The committee then reviewed the recommendations from last year.

**Review of Past Recommendations**

1. **The new Electronic IEP**

The subcommittee will report to the Autism Commission the work that was done on this project, that written recommendations from the subcommittee to be incorporated into the new IEP were sent to DESE, and that we will continue to follow this issue and report updates to the Commission as we receive them. We will keep this as an ongoing recommendation for the subcommittee, as the new IEP project is still in process.

1. **Addressing the shortage of ABA providers Statewide**

The committee discussed several factors that impact the number and quality of aba providers statewide. Concerns included serviced delivery issues, varying standards for agencies, standards for caseloads. The possibility of incorporating RBT programs into vocational high schools was mentioned. Dr. Johnston suggested that this be an ongoing issue for us to work on, but that we may not be ready to form a specific recommendation at this time. The subcommittee can share the survey work done to date on this issue with the Autism Commission.

1. **Decreasing wait times for evaluation and diagnosis of ASD**

Ms. Rafferty-Butterfield provided an update on the Early Intervention pilot program using the Rapid Interactive Test for Autism in Toddlers. Training for clinicians in the western part of the state is underway, and Cambridge Health Alliance is partnering. There were questions about obtaining data about the rate of delay in diagnosis and treatment broken down by demographics to get numbers on the underserved population and the racial disparity in the system. It is unsure how much of that data is collected. Cultural barriers are a factor. The committee agreed that looking at this data would be helpful to assess where the gaps are so they can be addressed. This would first require reaching out to EI, DPH and MassHealth and facilities such as BMC to see if they track this data and if so, how they collect the data of this nature.

* A motion was made to make a recommendation to the Autism Commission to develop solutions so data can be collected and reported on regarding the age of diagnosis broken down by race. The subcommittee voted to make this recommendation to the Autism Commission.

**New Recommendations for the Autism Commission**

Dr. Johnston described the voting process the committee would undertake to determine new recommendations and priorities for year. Each member was asked to write down 2 pressing concerns for children with ASD in the birth to Fourteen age group. Answers were read, posted by subject matter on the walls, and then all members present voted on their top 3 choices for the group to focus on. The topics that received the most votes were: AAC device access, Inclusion issues, and services for children in the DCF system.

1. **Access to Augmentative /Alternative Communication Devices For Children with ASD**

Discussion points included the difficulty in getting devices outside of school settings through MassHealth, and need to obtain data.

* The subcommittee agreed to make a new recommendation to the Autism Commission to ask Mass Health to provide data about children who have received dedicated and non- dedicated AAC devices, broken down by race and language spoken in the home.

The subcommittee will also have a priority on this topic, to understand this process, with potential future recommendations which may include for DESE to keep data on this as part of the new electronic IEP, making access and use more parent friendly, and training and knowledge around AAC devices.

1. **Inclusion for Students with ASD**

Discussion points included obtaining statewide data in urban, suburban and rural settings, that is provided in a way that is analyzed by DESE to assess the level of access to inclusion of students with ASD. What do schools say are the barriers? What is the parent perspective about getting what they envision related to inclusion? How can ABA be done more in inclusive settings instead of substantially separate settings? A Best practices paper is being created now based to look at what exists and what schools should be shooting for is being done.

* The subcommittee agreed to make a new recommendation to the Autism Commission to ask DESE to provide data by broken down by race, language spoken in the home, and level of inclusion (full/partial or sub separate classroom) for students with ASD.

The subcommittee will also have a priority on this topic, to explore further the baseline, areas of excellence and current barriers to more inclusion for students with ASD.

1. **Children in DCF care with ASD**

Discussion points centered around training for DCF staff, where and how to present it, what has been done already by way of a webinar, and what would be beneficial for services coordinators and caseworkers, how to be sure there is ongoing training as staff turnover is high, collaboration with Autism Waiver staff, obtaining information on children in varying levels of DCF care with ASD, the privacy issues involved, the role of DDS in the cases of children with ASD in DCF, and what resources are available to them .

Ms. Kain suggested beginning with meetings with DDS and DCF to determine needs and she could facilitate with Sarah and Rob from the Autism Waiver program about providing training.

* The subcommittee agreed to put forth a recommendation to provide DCF staff trainings about ASD.

The subcommittee will continue to explore the needs and services available to children who have ASD that are in DCF care, and potentially make further recommendations related to requesting data on children in varying levels of DCF care.

Dr. Johnston reminded the subcommittee that we are continuing to expand to diversify membership, and any recommendations for potential new members are welcome.

With no further business to discuss, the meeting was adjourned at 12:00 pm.