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

**Subcommittee Meeting**

September 11, 2020 - 10:00am-12:00pm

Via WebEx

Present on Webex: Co-chairs Russell Johnston and Michele Brait, Joan Rafferty Butterfield, Michelle Poulin, Sarah Richmann, Zac Houston, Michelle Jenkins, 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. The meeting norms were read, and the subcommittee members on WebEx voted to approve the November meeting minutes unanimously.

**DESE update for School Reopening Plans for students with disabilities**

Dr. Johnston reviewed the initial guidance three tier model plan for school districts from DESE. He also highlighted the key concepts for the guidance for districts for the fall.

 1. All services needed would be delivered regardless of the model.

2. Parent engagement would be a focus. Communication would be clear and there would be documentation rather than notification from teacher to parent, especially if IEP services were going to be delivered differently.

3. If services are to be remote, they must be robust, synchronous, and additional asynchronous work would be supplemental, and not the means of primary instruction.

4. There will be in person learning for the highest need and preschool students. Onsite services will be provided in the home and community if services in school are not possible.

A compensatory service document will be developed to look at needs for students that may be above and beyond general support services. School districts locally would decide which model to use.

 DESE is now focusing on providing technical support to districts and families. Some examples include a mobile response unit for cluster testing, hotline to report cases so technical support can be given, and webinars on remote assessments.

**Other Agency Updates**

Joan Rafferty Butterfield gave an update on EI services during the pandemic. She shared that for those receiving services that were insurance funded, companies were flexile with billing, telehealth, and extension of services for children turning 3. Home visits continued for very complex cases, and in Phase 3 there were more in person specialty agency sessions. For EI state funded, the services consisted mainly of telehealth visits. DPH guidelines stated telehealth was the preferred method of service delivery unless it was determined that in -house was more appropriate. Referrals kept coming in for diagnostics, and there is currently a backlog for receiving a diagnosis and getting services.

DPH developed a flow chart document that was used by EI to assist families and agencies in determining if it was viable for a home visit service delivery. Beacon services shared their model of small cohorts consisting of 8 families, 2 providers and a BCBA.

Sarah Richmann gave an update on the DDS waiver program. They got federal approval for telehealth quickly during the pandemic. There were limited home services provided, and remote learning was very challenging for high need students. There was some training on practicing wearing masks. Many children were not able to sit long enough to access remote learning, and there were many reports of behavioral regression. It is expected there will be a similar jump in behaviors once school begins. The meal delivery component was a positive, and anyone aging out of the program got extended until February 2021.

Zac Houston spoke about Boston Public Schools. Some families were working with the district to get support while the children were home. Behaviors were increased with the students home all day. The wait lists are very long for ABA home services. There is a capacity issue, getting staff to homes and incorporating the travel component and al shortage of trained ABA staff.

Community service as an alternative option to home services was discussed. Places like YMCA, and libraries who already follow the health guidelines, could be options for service delivery. DESE has teamed up with EEC for learning pods to combine groups for oversight of remote learning. Consideration must be given to social emotional learning and home support for families.

**Barriers to getting students educated**

Dr. Johnston asked the subcommittee for thoughts on other potential barriers to education

In a remote or hybrid model. Access, equity, racial equity, language access, technology issues and parent engagement were all mentioned.

Regarding technology supports, DESE will be putting out further guidance documents. Boston Public Schools has telephone interpretation. MRC had a recent meeting about setting up a hotline to assist families with technology.

Parent engagement was determined to be a major issue and the subcommittee discussed possible ways to increase parent interaction within districts. Some suggestions included using the SEPAC to inform membership and share information, possibly with the assistance of FCSN. Virtual access to meetings may increase membership. Use of other non- profit agencies that already have a relationship with the families (ARC, Autism Resource Center) could be helpful in reaching out to parents. In the city, word of mouth information sharing within the community has been utilized. Parents talking with other parents that they trust on these issues to become more involved.

For concrete next steps, DESE could expand its mailing list to other agencies, and put guidance out in parent friendly verbiage to be distributed. Non-profits and community centers could disburse to their members. The expanded list could be shared with our subcommittee for further suggestions before distribution, and a parent fact sheet could be sent to all of those agencies.

The districts would have responsibilities in this area as well. They are busy training the teachers for remote learning but need to also consider trainings for parents. It would be important to ask what the families think they need to have better access and engagement. Regulations for students are in the process of being developed which will drive regulations for families.

**ASD Related Issues**

The subcommittee discussed ASD specific issues. As a result of students being without in person learning for over 6 months, there has been increased regression, higher ER visits for behavior related events. The impact on families is significant having the student home all day, off typical schedules and without support staff. Some families need support but have concerns about letting staff into the home for health reasons. They may be more open to going to a community center to meet with staff. Parents need some choice around education options, so they are comfortable with the level of risk a model presents and that impact on risk of exposure. What are ways to build trust with families to have them feel in person learning is safe?

Distributing facts about COVID research and the measures being taken to prevent the spread could help parents feel more confident. Guidance from districts on the day to day plan could be shared in a video or letter to parents. Taking small steps toward in person learning, being able to visit the classrooms, and have an extended transition phase may also make families feel more comfortable moving toward in person learning for the high need population. Providing information around IEP services and how they are being delivered in each model would be helpful to parents.

**Next Steps**

1. In Home Services - Sarah Richmann and Joan Rafferty Butterfield will share resources they have to help put together information to develop practices that are endorsed and can be put out as guidance.
2. Parent Engagement – A compensatory letter will be developed and translated that will go to community organizations to share with families.
3. Ideas to support Parents- Ongoing engagement and listening, parent training and troubleshooting from districts. Invitations to families to observe models in person and through videos. Extended transitions for families to feel comfortable. Sharing research information with families to build confidence. Looking at and addressing the whole family needs and needs that may be specific to the ASD population.

With no further items on the agenda, the meeting was concluded at 11: 56 am.