Massachusetts Autism Commission

Meeting Minutes

February 24, 2022, 2:00 p.m.– 3:30 p.m.

Via Zoom

Autism Commission Members Present: Secretary Marylou Sudders (EHS), Carolyn Kain (EHS), Jane Ryder (DDS), Elizabeth Morse (DDS), Janet George (DDS), Rep. Christine Barber (HOU), Sen. Joan Lovely (SEN), Joshua Tavares for Sen. Ryan Fattman (SEN), Lori Joubert for Rep. Joseph McKenna (HOU), Matthew Connolly for Ann Reale (EOE), Kate Ginnis (EHS), Terri Anderson for Kathy Sanders (DMH), Christine Hubbard, Russell Johnston (DESE), Bronia Clifton (DHCD), Emily White (DPH), Mary Price (DHE), Michele Brait, Katherine Canada (DCF), Vivian Pham for Toni Wolf (MRC), Jo Ann Simons, Julia Landau, Dan Burke, Amy Weinstock, James Vander Hooven, Karen Wylie (OEA) and Janet Barbieri

Guests: Emma Vázquez (HOU), Hannah Mori (SEN), Bekah Diamond (EHS) and Michelle Harris (DDS)

Meeting Minutes: Dianne Lescinskas (EHS)

Approval of the Minutes from December 16, 2021

Secretary Sudders called the meeting to order and asked for a motion to approve the meeting minutes from the Autism Commission meeting on December 16, 2021. Ms. Weinstock made a motion to approve the minutes and Ms. Simons seconded the motion. A roll call was done with members approving the minutes and abstaining from the vote are the following members: Sec. Sudders, Hannah Mori, Lori Joubert, Bronia Clifton, Kate Ginnis, Mary Price, Matthew Connolly, Joshua Tavares, Emily White, Vivian Pham, Karen Wylie, and Janet Barbieri. Minutes from December 16, 2021 were approved.

Secretary Sudders discussed the 2021 draft report of the Autism Commission and on the past two years while now transitioning from a pandemic to an endemic. She asked that members of the Autism Commission think about what the experience has been like for individuals, families, and providers. The data will never be perfect but to think about lessons learned moving forward and together to identify data that is needed in the next several years. She asked that as members think about the draft report, to reflect on the past couple of years and to provide comments on the experience.

*Comments*

* Remote services worked for many and provided continuity but for some, it did not work for specific groups as some individuals are not able to access remote work
* Many silver linings with telehealth, increased access, and capacity, reduces stress of ASD individuals
* The ASD community is still in crisis with wait times for diagnosis – it was a problem two years ago but much worse now
* Adults with severe ASD cannot go to day programs due to staffing issues
* Families are under an enormous amount of stress
* Public education – family engagement is on a different level now and there is movement on how parents get their information on one platform
* Mental health needs of students are a concern – how to approach and support kids well – more work need to be done to address this issue

Secretary Sudders will provide a cover letter to accompany the 2021 Annual Report to reflect the comments from commission members.

*Announcements*

DESE is close to hiring an Ombudsman to respond to issues regarding special education. A person that will work with LEA’s and hospitals and answer to conflict. Working to support students in urgent situations.

DCF expressed deep gratitude to the commission members who helped disseminate the RFI – 50 responses have been collected thus far.

MassHealth procurement for Behavioral Health has hit the streets. The document has clear expectations that ASD individuals will be served. The Behavioral Health helpline will go live at the beginning of next calendar year. RFP will be out in March.

**Review and Approval of the draft 2021 Annual Report**

Ms. Kain discussed the Autism Commission 2021 draft report that was previously reviewed in December. She reviewed highlights and incorporated the updates that members asked for at the previous meeting. She also provided a timeline starting in March of 2020 summarizing what has occurred since the start of the pandemic in terms of support from state agencies and the financial relief provided throughout the pandemic.

The data request from Rep. Barbar and others is provided in the report. It was asked that the data from pre-pandemic compared to current data be included. Ms. Kain took data from the 2019 Autism Commission report and used it as a comparison to the current data. Other than that change, no other substitutive changes were made to the report.

At this point in the meeting, Ms. Kain opened it up to questions from the membership.

*Questions/Comments*

* The letter to accompany the Autism Commission report is a good solution
* Understanding that the data does not exist at this time and recommend to the commission that this data will be collected as we move forward
* Secretary Sudders commented on learnings from the pandemic as it exposed fragilities and strengths of a system. Across the board, race and ethnicity data is incomplete. In March of 2020 the healthcare system was required to report on race and ethnicity, and it has improved over time. There is a commitment to collect data on race and ethnicity for individuals with disabilities
* Recommendation that data is collected in a more systematic way
* Secretary Sudders will send a letter requesting an extension of the study on collecting demographic data and will cc’ the legislation members who are on the Autism Commission

With no further questions or comments, Ms. Kain asked for a motion to approve the 2021 Autism Commission report. Ms. Ginnis moved the motion and Ms. Weinstock seconded the motion. A roll call was made with Joshua Taveras and Lori Joubart abstaining from the vote. All other members present, voted to approve the Autism Commission 2021 report.

Ms. Kain asked that members comment on the needs moving forward as we move from the pandemic to an endemic.

* The need to prioritize workforce shortage
* The ABA Center Based Programs regulations be put on a faster track
* Brainstorm on increased workforce on all ages across the lifespan – look to get workers from across the globe
* Equitable service delivery for infants and toddlers across the commonwealth
* The role of colleges and state universities to help fill the workforce and pipeline
* The short-term use of money went into bonus’ and raises – long-term is the issue – rates need to be increased so people look at positions as a long-term career.
* Hoping the commission will continue to work with DCF on the recommendations from the OCA report – the commission has an important role in working with DCF this coming year
* DDS committed to data collection of race and ethnicity
* Reducing wait times for diagnosis
* MassHealth will continue to work on gathering more complete data on race and ethnicity to better serve the community

With no further business to discuss, Commissioner Ryder asked for a motion to adjourn the meeting, Mr. Vander Hooven moved the motion and Ms. Weinstock seconded the motion. The meeting was adjourned.