Massachusetts Autism Commission

Meeting Minutes

December 15, 1:00 p.m.– 3:00 p.m.

Via Zoom

Autism Commission Members Present: Jane Ryder (DDS), Carolyn Kain (EHS), Elizabeth Morse (DDS), Janet George (DDS), Rep. Christine Barber (HOU), Hannah Mori for Sen. Joan Lovely (SEN), Joshua Tavares for Sen. Ryan Fattman (SEN), Rep. Joseph McKenna (HOU), Ann Reale (EOE), Kate Ginnis (EHS), Terri Anderson for Kathy Sanders (DMH), Toni Wolf (MRC), Christine Hubbard, Russell Johnston (DESE), Bronia Clifton (DHCD), Emily White (DPH), James Vander Hooven, Michele Brait, Jennifer Chebator for Katherine Canada (DCF), Amy Weinstock, Julia Landau, Laurie Anastopouos, Ann Neumeyer, Karen Wylie (OEA), Mary Price (DHE) and Amy Kershaw (EEC)

Guests: Chris Peltier (DDS) Heather Morrison, Carol Gracia (EHS)

Meeting Minutes: Dianne Lescinskas (EHS)

 Approval of the Minutes from September 15, 2022

Commissioner Ryder called the meeting to order and asked for a motion to approve the meeting minutes from the Autism Commission meeting on September 15, 2022. Ms. Kershaw made a motion to approve the minutes and Ms. Weinstock seconded the motion. Ms. Kain asked if there were any questions or comments on the minutes and seeing none, a roll call was done with members approving the minutes and abstaining from the vote were the following members who were not present at the last meeting: Commissioner Wolf, Terri Anderson, Julia Landau, Ann Neumeyer and Jennifer Chebator. The minutes from September 15, 2022, were approved.

**Center Based Programs**

Commissioner Kershaw gave an update on the Autism Commissions recommendation for ABA Center Based Programs and oversight of programs. Since this issue arose, there have been three different Commissioners for EEC as well as the pandemic – this has impacted new initiatives. There has been progress over the last 6 months for oversight to Center Based Programs. EEC is hiring an ABA supervisor to oversee the new unit for fiscal year 2024. They are using the rest of this fiscal year to look at regulations and best practices and what it will look like moving forward.

If anyone has any resources, EEC welcomes input from this commission.

**Draft Annual Report Update**

Ms. Kain prepared a PowerPoint presentation to review the draft Annual Report. There will not be a vote on the report today, Ms. Kain will review the report and open the floor for questions/comments.

*DDS*

DDS has begun a data improvement initiative for collection of race data for all individuals served. Ms. Kain presented the data provided by DDS to be included in the Annual Report.

* It was asked if the DDS data could be broken down further to include ASD and ID and ASD only individuals. Ms. Kain pointed out the section of the report that breaks down those with ASD only and those with ASD and ID.
* It was asked if there was data on suburban vs urban areas in regard to race. This data is not currently available.

*MassHealth*

Ms. Kain presented the data that was provided by MassHealth – data regarding race and ethnicity was not available at this time.

Ms. Landau commented on the coverage of medically necessary treatments by MassHealth – in particular the dedicated and non-dedicated augmentative and alternative communication devices.

* MH is working on a new process for non-dedicated devices
* Many layers of challenges – creating a new system which Spaulding would be the first site of iPads ready to go to trial if a child meets the criteria – the child can keep the device – this would be a huge improvement over the burdensome process that is now in place
* Questions were asked about waitlist times, especially if a child has already been evaluated for a device and approved
* Ms. Ginnis will follow up this conversation offline with a few of the commission members

*MRC*

Ms. Kain presented data provided by MRC. They are working on a system of collecting data and looking at the disparities in race/ethnicity. The NexGen initiative will be looking at targeted outreach.

**Commission on Autism – COVID-19 Study**

Update: This study has not been completed because COVID data has not been systematically collected based upon an individual’s diagnosis or the by the subgroups identified in the Legislation.

The commission was charged with reviewing data by each major racial and ethnic group, primary language, sex, and economic status during the outbreak of COVID-19 and the recovery process on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color with autism spectrum disorder.

* Ms. Kain reported that the commission is not able to collect the data since it is not available – there is no information on who was getting services/supports based on race/ethnicity. Ms. Kain explained that services that were offered during the pandemic were offered to all individuals, the type of services varied and evolved over time from fully remote to partially remote and that agencies were still focused on restoring services to their pre-pandemic in-person levels. She also noted that whether or not individuals and their families accessed services was impacted by a myriad of issues, personal choice of whether or not to access what was being offered and workforce shortages to name a few.
* What we do know is that the service system pivoted during COVID-19 to address ASD individuals needs, and the state invested significant financial resources to address the needs of individuals with ASD of all ages.
* In 2020 state agencies did not collect this data and it is not possible to go back in time to gather data that does not exist, but moving forward there is now opportunity to collect additional data
* Rep. Barber asked if the report could reflect “why” the data was not collected and the plans to collect data moving forward. Ms. Kain said that it wasn’t collected because it was not part of the agencies data collection processes previously, but that she would ask each agency to describe for the report what changes they have made to their data collection processes to better gather data to address equity.
* MassHealth reported in the new 1115 Waiver application by CMS, health and equity are in the forefront – there is broad agency planning on capturing data to understand and better respond to equity
* DDS is prioritizing the collection of data and more outreach to minority communities
* DPH has this data and has been collecting it since 2009 – it was provided to Ms. Kain for the annual report, and will be included as another appendix. They have also done training with contractors on collecting the data
* The Birth – Fourteen subcommittee is looking at DEI data and will continue with opportunities on collecting additional data as well
* It was suggested that the appendixes, with data from state agencies, be more upfront in the report
* The report talks about COVID as static in 2020/2021 – how do we talk more about challenges with service recovery from the pandemic in the report
* Ms. Kain suggested that the state agencies give a brief report on data collection and efforts to improve in the future and she will include the agency updates in the report
* Question around data and if the discrepancies are due to late diagnosis. This could be a contributing factor
* DESE – they only collect primary diagnosis, not secondary
* There is no data to show specifics impact of COVID-19 but there is enough information to show the interventions that were offered and that was highlighted in the previous annual report
* Ms. Kain suggested a work group, of Autism Commission members, to look at the available data and make recommendations – suggestions were to make a recommendation to address current disparities, and if possible look at communities most impacted by pandemic
* Ms. Kain asked that Commission members reach out to her if they would like to be in the working group addressing the legislation, the next Autism Commission meeting would be in mid-January so the smaller group would meet prior to that meeting – she asked that the work group include state agency representatives
* For the annual report, it would make sense to summarize where we are now with the data and recovery efforts and acknowledge that we need more time to address the purpose of legislation to address equity– focus on the impact of the pandemic
* It would be helpful to have current data in the report and the agency summary on how they plan to address data collection moving forward
* MRC suggested that each subcommittee focus on DEI – it should be institutionalized in committee work – this was suggested as an option in addition to a working group
* Ms. Kain will email commission members regarding a work group meeting after she is notified who would like to participate
* Comments were made around the report not addressing waitlists for services and workforce issue – individuals being stuck at home – the urgency and severity of the impact is not coming through in the report – let the Legislature know the state of where we are now
* Ms. Kain reminded the commission members that the secretary did send a cover letter with the annual report last year that addressed concerns discussed above, and she said that similar information could be included this year
* Additional comments around the inequity in adult services as it relates to severe ASD, impact of workforce - the Legislature needs to know about the intensive staffing needed for individuals not getting services due to workforce crisis
* Ms. Kain and Adult subcommittee did try to gather data from MassHealth on DayHab programs and whether or not they are back to pre-pandemic levels but it doesn’t exist

**Next Steps**

Ms. Kain will get agency summaries on data collection for the report. She asked Commission members interested in the work group to reach out to her.

With no further business to discuss, Commissioner Ryder made a motion to end the meeting, and Ms. Weinstock seconded the motion. Meeting adjourned.