Massachusetts Autism Commission

Meeting Minutes

February 15, 2024, 1:00 p.m.– 2:30 p.m.

Via Zoom

Autism Commission Members Present: Undersecretary Mary McGeown, Michelle Harris (DDS), Carolyn Kain (EHS), Jane Ryder (DDS), Elizabeth Morse, Rep. Christine Barber (HOU), Mia-Haita James (EHS), Kathy Sanders (DMH), Toni Wolf (MRC), Christine Hubbard, Bronia Clifton (DHCD), Andrew Rome (EEC), Emily White (DPH), Heidi Gold (EOE), Karen Wylie (EOEA), Sen. Joan Lovely (SEN), James Vander Hooven, Ann Neumeyer, Jo Ann Simons, Laurie Anastopoulos, Julia Landau, Janet Barbieri and Amy Weinstock

Guests: Emily Camizzi, Rita Gardner, Dana DeShiro

Meeting Minutes: Dianne Lescinskas (EHS)

Welcome and Approval of the Minutes from December 12, 2023

Undersecretary Mary McGeown called the meeting to order and welcomed the members of the Autism Commission. She discussed completing and filing this report and how it will shape the work over the next year. She also thanked the autism commission members for the commitment and work being done.

Ms. Kain asked for a motion to approve the meeting minutes from the Autism Commission meeting on December 12, 2023. Ms. Weinstock made a motion to approve the minutes and Ms. Harris seconded the motion. Ms. Kain asked if there were any questions or comments on the minutes and seeing none, a roll call was done. Rep. Barbar abstained from the vote. The minutes from December 12, 2023, were approved.

Rep. Barbar thanked Ms. Kain for the data that does exist and is included in the Annual Report. She discussed the legislation that was passed in 2021 and the ability of the commission to make a recommendation to prioritize the use of existing data from their communities to look at communities that were disproportionately impacted by the pandemic.

Ms. Kain discussed that each subcommittee looked at the data that they currently have, and the 14-22 subcommittee did a deep dive on DEI data in regard to student placement in classroom settings, as well as equal access to after school programs. The DEI conversation is ongoing, and the state agencies are committed to expanding the way they collect data. It is important to address the use of the data and the inequities that we find from the data.

As for a recommendation in the report, it could go under “data collection” – this is what we are doing now, and this is what we will do in the future with the additional data. Ms. Kain will draft the language and send it out to the commission members.

Ms. Kain commented that the agencies collect data in different ways and some individuals are involved in multiple agencies which will create duplication in some areas. A charge of this commission will be getting data and understanding what direction the data will lead us – looking at what the data is telling us.

Ms. Kain also discussed equal access and how to reach more people to let them know what they may be eligible for. The Autism Commission created brochures in 6 different languages to help families by bringing information in one place – an overarching goal is to get information out, so individuals can access additional resources/information.

**Review of PowerPoint Presentation with Updated Data for Comparison**

Ms. Kain went through the slides and discussed the additional data that was added for comparison purposes.

It was asked if MassHealth could break down their numbers to include individuals ages 18-20 years old – the information is provided below. MassHealth covers ABA up until age 21 and a recommendation of the Healthcare Committee is to increase the coverage of ABA to over the age of 21.

MassHealth implemented coverage for ABA in June 2015. **In FY2022, *MassHealth spent a total of* $185.4M** for **7,917** members.

**In FY2023**, MassHealth spending on ABA services was **$188,711,817.** for **9,328** members.  **The FY2023** breakdown of the ages of the children is found on the table, below.

|  |  |  |
| --- | --- | --- |
| **Age** | **# of children served** | **Amount Paid** |
| 0-5 | 4812 | $106,040,993 |
| 6-12 | 3518 | $66,541.986 |
| 13-17 | 786 | $12,093,578 |
| 18-20 | 212 | $4,035,260 |
| Total | **9,328** | **$188, 711,817** |

**Nondedicated Devices**

In **FY22**, MassHealth issued **87** dedicated speech generating devices (SGDs) to individuals with ASD and **5** non-dedicated devices. In **FY23**, MassHealth issued **110 dedicated speech generating devices (SGDs) to individuals with ASD and 4 non-dedicated devices**. MassHealth has partnered with a Speech Language Pathology clinic that has two locations to pilot the improvement of accessing non-dedicated devices. To date, MassHealth is also working with 6 other Speech Language Pathology clinics to implement this process. MassHealth is working with a new IT company to assist with setting up all the technical components of the devices, before delivering them to the clinics. The goal remains that providers will maintain a stock of non-dedicated devices and cases to allow MH eligible members to trial them and, once authorized, get a device directly from their provider. **In 2024**, MassHealth will be posting a Request for Applications (RFA) for any MassHealth Enrolled Speech Language Pathology clinic who would like to apply to assist with accessing non-dedicated devices to MassHealth members. MassHealth appreciates the partnership of the provider community and anticipates that this program will increase access to the devices.

*Discussion*

* It is a challenge for individuals to get the information.
* Ms. Kain has met with MH to address the barriers that individuals and families face.
* Ms. Kain will continue her discussion with MH and update the Healthcare Subcommittee

**MRC Data/NexGen**

MRC is currently operating a 5-year federal demonstration grant known as NextGen Careers. Individuals with ASD are a target population for this project. NextGen will focus on serving young adults ages 18 to 30 with the goal of evaluating a new model for VR services designed to lead to employment outcomes with higher wages and career pathway opportunities in fields such as STEM. As of June 30th, **346** individuals had enrolled in NextGen, of these, a total of **109** **(33%)** are individuals with ASD.

*Discussion*

* Commissioner Wolf discussed NextGen and additional data that could be useful – they are using a different type of outreach to specific communities. The lessons learned here can be maximized elsewhere.
* MRC has the most robust data, and it is used in its’ decision making.

**Roll Call Vote for Annual Report**

Ms. Kain asked for a motion to approve the Annual Report as presented with additional recommendation to look at existing data and continue to look at DEI and work with the agencies to increase data collection. Commissioner Ryder made the motion to approve the annual report and Dr. Sanders seconded the motion. A role call was done with all members approving the Annual Report.

After voting Ms. Landau asked about adding language in the chat that would address data collection, DEI and inequitable impact during COVID. Ms. Kain again explained that data had not been collected during COVID as agencies were focused on the delivery of remote services during that time and issues like PPE and a gradual return to in-person services.

Ms. Landua asked about also adding something that reflects statutory requirements, ie. The commission will use the data being collected as a baseline measure to inform potential interventions to improve access to equitable services, and the commission shall make recommendations to address identified inequities including, but not be limited to establishing periodic benchmarks, recommendations and cost estimates for a coordinated system-wide response and any recommendations for regulatory and legislative actions.” Ms. Weinstock endorsed the language proposed by Ms. Landau and Rep. Barbar agreed with it as well. Ms. Kain said she would review Ms. Landau’s language as well as the language from Ms. Gardner and send a proposed recommendation out to members, and members would respond directly to her with their agreement or any questions or concerns.

**Other Business**

* Ms. Weinstock discussed barriers in accessing a ASD diagnosis and announced there will be a summit on May 9th, in person, to brainstorm on ways to get more pediatricians involved with diagnosing. This will be an invite by email to a small group. Connect with Ms. Weinstock if interested in attending.
* Ms. Gold discussed an interagency group that will increase the use of ASQ and data collection.

Motion to adjourn the meeting. With no further discussion, the meeting was adjourned.