Massachusetts Autism Commission

Meeting Minutes

December 12, 2023, 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), Emily Camizzi for Rep. Christine Barber (HOU), Mia-Haita James (EHS), Kathy Sanders (DMH), Toni Wolf (MRC), Christine Hubbard, Russell Johnston (DESE), Bronia Clifton (DHCD), Amy Kershaw (EEC), Emily White (DPH), Sacha Stadhard (LWD), Heidi Gold (EOE), Karen Wylie (EOEA), Johanna Wakelin for Sen. Joan Lovely (SEN), Jo Ann Simons, Mary Price (DHE) Michele Brait, Katherine Canada (DCF), Laurie Anastopoulos, Julia Landau, Janet Barbieri and Amy Weinstock

**Guests:** Jared Ramos (DDS), DesNeiges Harkness and Chris Peltier (DDS), Josh Greenberg (DMH)

Meeting Minutes: Dianne Lescinskas (EHS)

Welcome and Approval of the Minutes from November 28, 2023

Undersecretary Mary McGeown called the meeting to order and welcomed the members of the Autism Commission.

Ms. Kain asked for a motion to approve the meeting minutes from the Autism Commission meeting on November 28, 2023. Ms. Kershaw made a motion to approve the minutes and Ms. Hubbard seconded the motion. Ms. Kain asked if there were any questions or comments on the minutes and seeing none, a roll call was done. Commissioner Ryder abstained. The minutes from November 28th, 2023, were approved.

**Review of Draft Annual Report**

Ms. Kain shared a PowerPoint presentation with updates of the Annual Report – the recommendations were discussed at our last meeting. She shared updates from the respective state agencies and data breakdowns that include DEI. After this review and meeting, the Commission will meet on February 15th for final approval. The Annual Report is due to the legislation on or before March 1, 2024.

**DDS Data**

* From November 2014 to October 2023, **4500** “newly eligible” individuals with ASD only met the DDS criteria for eligibility as a person with autism and functional impairments (in three or more of seven life areas). As of October 2022, **2247,** individuals were enrolled in DDS services. Of the **4500** individuals eligible, **2625** are currently enrolled in DDS services.
* Individuals with an intellectual disability (ID) and ASD are also eligible for DDS services. Since eligibility was expanded for individuals with ASD, DDS also began separately tracking the number of individuals with co-occurring ASD and ID. The number of new individuals with ID and ASD as of October 2023 is **2366**.

***Comments/Questions***

It was asked if the numbers given could also be represented in percentages that would track growth year after year. Ms. Kain pointed out that data was provided in the 2022 annual report that was pre-covid for comparison with recent data. Ms. Kain said that she can add back in data from the previous year, as a measure of comparison.

**Turning 22**

* The **FY24** “Turning 22 budget” is funded at $105,653,241. In previous fiscal years the DDS T22 budget was projected ***ONLY*** for individuals turning 22 in that specific fiscal year. In FY22 the Department adjusted the funding model to allow for more flexibility.
* For FY24, there are **443** **individuals with ASD only** in this year’s Turning 22 class, which is **32%** of the FY24 Turning 22 class. There are also **308** **individuals with ASD and ID**, which is an additional **22%** of the FY24 Turning 22 class.

***Comments/Questions***

Given the number of “missing race” what work is being done to gather that data.

DDS has not collected this data in previous years and there is a new effort to collect it moving forward, which is a dramatic improvement – there is a new data base that will be implemented by DDS, to assist with identifying any issues with equity in services. Ms. Kain said that data collection processes were included in the 2022 report, and that information could be included in the 2023 report.

**DDS/Umass ICI**

* DDS, through a partnership with UMASS Boston Institute for Community Inclusion, collects snapshot employment outcome data every year in the month of April from providers who deliver individual and group employment services.
* Based on the employment data collected from providers in April 2022, there were about **2,338** individuals employed individual jobs,**1,711** individuals employed in group employment, and **17** individuals that reported as Self Employed.
* This represents **37.6%** of those participating in day and employment supports as employed in integrated, competitive employment at some level.
* Data indicates the average hourly wage for individual jobs is slightly higher ($15.29) than the Massachusetts minimum wage and below for group supported employment ($13.51).
* DDS is committed to expanding their CBDS “Without Walls” program model which is delivered in small groups exclusively in the community.  DDS is dedicated outcome to supporting return-to-work efforts through strong partnerships and collaboration with individuals, families, businesses, provider agencies, community organizations, and partner administrations.

***Comments/Questions***

* Usually, this data from ICI is a year behind – it takes a bit longer to collect the data.
* The numbers are going up as we come out of the pandemic.
* CBDS model is being out in the community and DDS is happy with the progression of Without Walls

**MassHealth Updates**

* MassHealth implemented coverage for ABA in June 2015. In FY2023, preliminary claims review shows that MassHealth spending on ABA services was $**148, 834,344.46 for 8409 members.**

***Comments/Questions***

* Amy Weinstock stated that there is still a recommendation by the Health Committee to expand coverage 21+, and there has been a bill filed on this issue. Ms. Kain stated that there are significant expenditures by MassHealth on ABA under age 21, and because of that MassHealth has been unwilling to expand coverage to adults.
* It was asked if the data could be shown on the cost over the years. Ms. Kain responded that she will add back in the 2022 cost by MassHealth. Mi-Haita James also said that she would verify the current amount provided by MassHealth and update the report.
* Ms. Kain pointed out that this data only includes members with MassHealth receiving ABA – there are individuals receiving ABA through private insurance, through the Children’s Autism waiver Program, the DDS/DESE residential prevention program, and in school.
* Ages 0-3, the data does not include individuals getting ABA through Early Intervention, as that is a separate program managed by DPH.
* Amy Weinstock asked if MassHealth could provide a separate number for 18–20-year-olds. Mi-Haita James said she would ask MassHealth for a more refined breakdown by age.
* ABA services are critical at a young age – other services get supplemented when individuals get older – not surprised to see higher numbers of ABA at a young age – other services replace ABA as individuals age and enter school.
* There are still older adults who need ABA – MH is engaging in discussions of ABA for 21+

**MassHealth – Dedicated and 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**.
* Utilizing ARPA funding, MassHealth has partnered with Mass Advocates for Children and Speech Language Pathology providers to develop and implement a process to improve access to non-dedicated devices.

***Comments/Questions***

* There is still frustration with families on the complications on receiving these devices. Speech therapists say the process for families is cumbersome – the Autism Insurance Resource Center hears about the difficulties as well.
* Spaulding did a pilot program to ensure getting devices to families, but the numbers remain low.
* Ms. Kain will reinitiate conversations with MassHealth. She explained that she has had many meetings on this issue with MassHealth but those participants from MassHealth are no longer there. Ms. Kain asked that the information known to the Insurance resource Center and Mass Advocates from families about the difficulties they are experiencing be shared with MassHealth to aid in addressing any barriers.
* Ms. Kain said she would check in with MassHealth on their efforts regarding this issue and update the annual report.

**DDS and DMH Fellowship**

* The total number of DDS/DMH Fellowship evaluations conducted for the 2022-2023 academic year was seven **7** with the Massachusetts General Hospital Autism Spectrum Disorder Fellowship site, and ten **10** at the UMass Memorial Health Center (UMMHC) Neuropsychiatry Clinic, Center for Autism and Neurodevelopmental Disorders (CANDO)site.

***Comments/Questions***

* Ms. Kain will add the previous year’s data to the report.

**MRC Data**

* In FY23, MRC served a total of **3,400** **Vocational Rehabilitation (VR) consumers with ASD overall.**
* In terms of race and ethnicity, these individuals are broken down (some identified as two or more races) as 2,946 (86.6%) White, 308 (9.1%) African American, 273 as Hispanic (8%), 151 as Asian/Pacific Islander (4.4%), 27 as Native American (0.8%), and 54 (1.6%) chose not to identify their race.
* At the time of application to VR services, 60% identified their primary source of support as Family or Friends, 28.5% as Public Support/Benefits, 10.7% as personal income, and 0.8% as other sources.
* Regionally, 38.8% are in the North District, 31.5% in the West District, and 29.7% in the South District.
* **Of these 3,400 consumers, 547 were enrolled in Post-Secondary Education during FY23**.
* In terms of race and ethnicity (assuming some identified as having two or more races), these 547 individuals in post-secondary education are broken down as 477 White (87%), 41 African American (7.5%), 38 Hispanic (6.9%), 36 Asian/Pacific Islander (6.6%), 4 Native American (0.7%), and 2 chose not to identify their race (0.4%).
* These individuals are enrolled in degree-bearing post-secondary education programs based on their latest Individualized Plan for Employment (IPE) with MRC

***Comments/Questions***

* Last year it was asked if data could be broken down by region – it is included with the data provided for the report.
* Last year’s data was pre and post Covid numbers, the 2022 data will be added.

**MRC – Pre-ETS/688/OneMRC**

* MRC has 35 providers of Pre-Employment Transition Services (Pre-ETS), which provide job exploration counseling, workplace readiness trainings, workplace learning experiences, counseling in post-secondary training opportunities, and self-advocacy to students aged 14-22.
* In FY23, **1,013** VR eligible consumers with ASD received services from its Pre-ETS vendors, of which **925** received a work-based learning experience.
* MRC has 35 providers of Pre-Employment Transition Services (Pre-ETS), which provide job exploration counseling, workplace readiness trainings, workplace learning experiences, counseling in post-secondary training opportunities, and self-advocacy to students aged 14-22.
* In FY23, **1,013** VR eligible consumers with ASD received services from its Pre-ETS vendors, of which **925** received a work-based learning experience.
* In FY23, MRC **received 190 referrals** through the **688 Process for individuals with** **ASD** and served **448 individuals with ASD** in its **Transition to Adulthood (TAP) program**, which is operated by the Independent Living Centers (ILCs) to provide peer-driven transition services to youths with disabilities.
* However, we only have information on **329** of those consumers in terms of race and ethnicity.
* These **329** are broken down as 186 White, 27 African American, 16 Asian/Pacific Islander, and 53 Hispanic ethnicity, as 33 chose not to disclose and 22 selected “Other/Multiple”.
* MRC and its employment providers continue to work on strengthening their data collection processes utilizing its MRC Connect integrated eligibility program and the agency’s ongoing project to develop a new and modern data system for its VR and CL divisions known as OneMRC.
* These efforts will focus on including retention data for individuals served with ASD as well as focusing on considerations of culture, race, linguistics, gender identity and socio-economic status in data collection and analysis. MRC also plans to expand disability data collection for Potentially Eligible Pre-ETS students to include the ability to break out and track data on consumers for ASD. This project should be completed in July 2024.

***Comments/Questions***

* Families sometimes do not understand the 688 process – during the pandemic the BTP discussed with DESE the on-going issue of late referrals by school districts – DESE does remind school districts of the importance of filing the 688 at least two years prior to a student graduating or leaving school, nut this remains an issue.
* 688 is a referral process, individuals then need to be found eligible by DDS, DMH or MRC and service plans developed, which is why the 2 years in advance of them leaving special education is so important. Individuals can also apply directly to an agency.
* Not included in this report, but MRC is looking at wage earnings though ethnic groups – seeing a disparage and will look at this data and hope to share in next report.
* MRC discussed NexGen and STEM careers – parent partners reaching out to other parents and getting referrals from DDS.

**14-22+/Employment Updates**

In March 2023, the Department of Elementary and Secondary Education (DESE) released a new statewide IEP, to be fully implemented in fall 2024. The new IEP contains expanded information and questions about the duration of an eligible student's school day or school year. DESE developed an accompanying "Technical Guide" that provides direction to IEP Teams for completing all sections of the IEP, including the need for an extended day or extended year. DESE is in the process of developing additional resources to support families with the IEP process.

* The 144-22+ subcommittee met with DESE and reviewed the work that is being done by DESE that also addresses the two recommendations put forward by the subcommittee.
* Ms. Kain will work with Mr. Johnston on the language to include in the report, regarding how DESE is addressing the concerns in the 14-22+ subcommittee’s recommendations.

**Questions and Comments**

* Ms. Landau asked if we could circle back to the data on DEI and if there is an update to the legislation that was included in the report last year. The legislation asked the commission to look at data for access to services for individuals and look at inequities, and to make recommendations on the inequitable impact during COVID.
* Ms. Kain responded that the request for data had gone out to the respective agencies immediately after the legislation was passed. Ms. Kain pointed out that the legislation was passed in the fall and a report was a due just a few months later in January.
* We learned that the data systems were not as robust as we would have liked them to be, during Covid the state agencies needed to pivot their work (PPE, remote services etc.) and collecting data was not a priority at that time. State agencies were focused on helping individuals and families in ways that were unprecedented for them and their providers.
* There was a small working group of the Commission to review the legislation that was filed, determine what, if any, recommendations could be made. The working group learned that data didn’t exist, and it was not possible to make recommendations to address any inequities caused by the outbreak of COVID-19. Any data that did exist was included in the annual report, and how agencies were improving their data collection processes was also included in the 2022 annual report.
* DESE also has appendices with DEI data included in the report.
* In prior years, Secretary Sudders included a cover letter to the report that discussed the challenges of Covid and the workforce challenges – hoping an executive summary could be included in this year’s report to give context to the workforce issues and DEI – it will help to let the Legislature know the focus of the commission.
* Ms. Kain highlighted that programs are still in recovery from the pandemic, workforce issues cannot be overstated, and that some of the most severely impacted individuals haven’t returned to programs.
* Ms. Kain said that requests have been made to previously to MassHealth for the data on the number of individuals returning to programs (DayHab). MassHealth tried to get this data from their providers, but it was not available, and they received low responses overall to inquiries regarding this information.
* DDS does track utilization and does know who is back and can report out the utilization of services. - DDS services individuals with ASD and without ASD, and the information on utilization will not tell us if individuals are back full-time or only part-time.
* DCF shares the intersection of workforce issues and ASD with DDS. Katherine Canada said it is difficult to get individuals out in the community without the support – without MAP certification, they cannot take individuals out – double layer of inclusion issue – need more MAP certifications are needed to not isolate individuals.
* Ms. Landau asked if we could close the loop on the legislation and give an updated summary on what agencies are doing now and the future plan. We still have a duty to look at data that is available and address the inequities. Ms. Kain responded that the information on what state agencies are doing to collect data and how data collection is being enhanced and was included in the 2022 annual report of the Commission.
* Ms. Kain recapped the previous efforts that were made regarding the study, which were comprehensive, but data wasn’t collected during the pandemic – we cannot make a recommendations regarding information that was not and is not available. Rep. Barber sponsored the bill and was involved in the working group of the Commission regarding this issue. The working group agreed there was no way to make recommendations about inequities that may have existed during COVID. The working group also agreed that the Commission should look at data as it becomes available to us, and where appropriate make recommendations. Ms. Kain said that current and future efforts to collect data can be added back into the report, as they were already included in the 2022 annual report.

With no further business to discuss, the meeting was adjourned.