**Massachusetts Autism Commission**

*Meeting Minutes*

November 20, 2024 - 10:30 a.m. – 11:30 a.m.

*Via Zoom*

**Autism Commission Members Present**: Undersecretary Mary McGeown, Michelle Harris (DDS), Carolyn Kain (EHS), Tim Cahill (DDS), Joshua Tavares for Sen. Ryan Fatman (SEN), Rep. Christine Barber (HOU), Rep. Joseph McKenna (HOU) Jamie Nathan for Sen. Joan Lovely (SEN), Mi-Hata James (DMH), Toni Wolf (MBY), Jen Chebator (DCF), Christine Hubbard, Iraida Alvarez (DESE), Jocelyn Brown (EEC), Bronia Clifton (EOHLC), Emily White (DPH), Sacha Stadhard (EOL), Mary Price (DHE) Jo Ann Simons, Faith Ambrose (EOE), Janet Barbieri, Laurie Anastopoulos, Ann Neumeyer, Joanne Flatley, Rita Gardner, Zachary Houston, Jessica Sassi and Amy Weinstock

**Meeting Minutes**: Dianne Lescinskas (EHS)

**Welcome and Approval of the Minutes from May 16, 2024**

Undersecretary Mary McGeown called the meeting to order and welcomed the members to the meeting. Ms. Kain recognized that there are new members of the Autism Commission and asked that they introduce themselves. The new members present at the meeting were as follows; Tim Cahill, Faith Ambrose, Jocelyn Brown for Aimee Smith Zeoli, Joanne Flatley, Zachery Houston, Rita Gardner and Jessica Sassi.

Ms. Kain reviewed the agenda for the meeting and then asked for a motion to approve the meeting minutes from the Autism Commission meeting on May 16, 2024. Ms. Hubbard made a motion to approve the minutes and Ms. Gardner 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 Rep. Christine Barber, Tim Cahill, Jocelyn Brown, Faith Ambrose, Janet Barbieri, Joanne Flatley, Rita Gardner, Zachery Houston and Jessica Sassi abstaining from the vote – all other members approved the meeting minutes. The minutes from May 16, 2024, were approved.

Undersecretary McGeown thanked the members for sharing their thoughts on the work of the Autism Commission and the subcommittee work. As the commission moves forward in the work, she wanted everyone to look at how we can be effective in the work and put forth recommendations that are concrete. She asked that the members look at if they are organized in the right way to do the work and if not, how to get there; if yes, what to we need to do to make progress.

***Comments***

* Need a framework to better understand how to move forward with priorities
* How does the work drive the structure of subcommittees
* Subcommittees have done a lot of work thus far and the work is appreciated – move forward and acknowledge the work that has been done
* The slide deck has recommendations as well as priorities that outline the work of the subcommittees

**Autism Commission Recommendations and Priorities**

(*slide deck presentation*)

A few Commission members asked for the presentation of slides be done in a timely manner so that the discussion of subcommittee work has enough time for a thorough discussion.

**Birth-14**

* **DESE IEP Improvement Project**That the Birth to 14 Subcommittee will provide input and feedback informed by stakeholder engagement to the Department of Elementary and Secondary Education on its implementation of a new IEP to address issues related to students with autism spectrum disorder focusing on considerations of culture, race, linguistics, gender identity, and socio-economic status.
* **Level of Service and Age of Initiation of Services with Early Intervention**That the Birth to 14 Subcommittee will review all available data about the amount of services provided to toddlers diagnosed with autism and enrolled in the Part C/early intervention system, disaggregated by race/ethnicity, primary spoken language.
* **Transition from Early Intervention to Special Education**That the Birth to 14 Subcommittee will examine available information related to the transition of children with autism spectrum disorder from early intervention to special education, with a focus on the timeliness of this transition and the continuity of supports.
* **Child Safety**That the Birth to 14 Subcommittee will facilitate the sharing of resources that might be available for communities, schools and individual households to improve safety for students with autism spectrum disorder, particularly aimed at addressing concerns such as wandering, bolting, accidental drowning, psychosexual health.

***Comments***

The Northeast ARC was awarded 70k, through the ArcTank to establish the Water Wise Program at the YMCA

**Adult Subcommittee**

* That funding be increased for adults with ASD only to enable DDS to provide services for adults with ASD only who became eligible for services under the Autism Omnibus Law, but who have not been able to access services because of limited funding for this population.
* That DDS and DMH remove barriers to dual eligibility for those individuals with ASD and a mental health disorder especially when there is conflict concerning diagnosis.
* That DDS develop alternative eligibility requirements for older adults with ASD only who may not have diagnosis records or school records because of their age.

***Priorities***

* **Expand Access to Resources for Aging Autistic Individuals, including those who were not eligible for services prior to 2014, and their Aging Caregivers and Support Networks**Encourage the Department of Developmental Services (DDS), MassHealth and other agencies to develop and disseminate a resource/information packet targeted to individuals aging with autism and their natural support networks and caregivers, including those who may not have been eligible for services prior to 2014.  
    
  Identify existing life care (including healthcare) navigation, coordination and management resources–both public and private– and ways in which these resources can be funded and grown on a systemic basis.

***Priorities***

* **Expand Access to Resources for Aging Autistic Individuals, including those who were not eligible for services prior to 2014, and their Aging Caregivers and Support Networks**Encourage the Department of Developmental Services (DDS), MassHealth and other agencies to develop and disseminate a resource/information packet targeted to individuals aging with autism and their natural support networks and caregivers, including those who may not have been eligible for services prior to 2014.  
    
  Identify existing life care (including healthcare) navigation, coordination and management resources–both public and private– and ways in which these resources can be funded and grown on a systemic basis.
* **Examine Barriers to Accessing Services, including Healthcare Services, Created by Late Diagnosis of Autism Spectrum Disorder (ASD)**Explore ways to effectively reach out to those aging with autism who were not eligible for services prior to 2014 to provide information about eligibility and services.  
    
  Explore issues around record keeping and the nature of required diagnostic information, especially for those aging with autism who were not eligible for services prior to 2014.  
    
  Expand access to diagnostic resources in healthcare for adults with autism.
* Ensure that adults with ASD and behavioral health (BH) needs have appropriate access to the full BH care continuum, inclusive of diversionary and hospital-level care.  
    
  Ensure that adults with ASD have access to appropriate, high quality, medically necessary treatment options.  
    
  Collaborate with the Autism Commission’s Healthcare Subcommittee in the above work and the Healthcare Subcommittee’s work to expand training of healthcare professionals on ASD and appropriate strategies for assisting individuals with ASD focusing on considerations of culture, race, linguistics, gender-identity and socio-economic status. (See the Healthcare Subcommittee’s 2024-2025 Priorities.)
* **Continue to Track Issues with Medicare Coverage for Dual Eligible Individuals with Autism and other Autistic Individuals Covered by Medicare**Stay informed about the work of the Insurance Resource Center for Autism and Behavioral Health and efforts of other organizations and policymakers regarding potential options to remedy existing gaps in health insurance coverage for autistic adults who have Medicare as their primary insurance.

**Healthcare Subcommittee**

**A*utism Spectrum Disorder (ASD) Treatment Access and Coverage***

* + Expand access to diagnostic resources for families.
  + Expand providers who can diagnose ASD for purposes of ABA medical necessity requirements.
  + Provide diagnostic training for primary care providers to reduce waiting times.
  + Train school psychologists, social workers, counselors, Speech Language Pathologists, OT’s and other professionals on how to support the diagnostic process.
  + Increase access to diagnostic services and supports for older adults, gender diverse, and transgender individuals.
  + Increase post-diagnosis resources, information, and supports for families.
  + Work with Early Intervention programs to ensure that prior to graduating from EI, children with ASD receive diagnostic evaluations that meet medical necessity requirements to allow for access to services after EI.
  + Coordinate efforts with Specialty ASD clinics to ensure that patients with more complex needs and profiles can be evaluated in a timely and efficient manner.
  + Ensure that individuals with ASD and behavioral health (BH) needs have appropriate access to the full BH care continuum, inclusive of diversionary and hospital-level care.
  + Ensure that individuals with ASD have access to appropriate, high quality, medically necessary, culturally responsive treatment options.
  + This includes ensuring that individuals over the age of 21 years with ASD, who have been receiving intensive school- and home-based services, are able to access appropriate, high quality, medically necessary treatments, including, but not limited to, applied behavior analysis.

**Expand Training of Healthcare Professionals**

* In addition to providing diagnostic training for primary care providers (under #1) The Healthcare Subcommittee will continue to explore the expansion of existing ECHO ASD programs and other training on ASD and appropriate strategies for assisting individuals with ASD focusing on considerations of culture, race, linguistics, gender identity and socio-economic status.
  + Behavioral Health Mobile Crisis/Emergency Service providers
  + Community Behavioral Health Center staff
  + Children’s Behavioral Health Initiative staff
  + Helpline/Hotline (including the Behavioral Health Help Line- BHHL) personnel
  + Hospital personnel and trainees, including Emergency Room personnel and trainees
  + Dental providers

**Housing Subcommittee**

***Priorities***

* The Housing Subcommittee will develop case studies of existing state-funded housing projects for individuals with ASD to assist the affordable housing field in Massachusetts in planning and developing sound affordable housing projects for individuals with ASD. Case studies will provide information on public and private financing sources, costs, design features, development and operational innovations and challenges.
* The Housing Subcommittee will track the implementation of the Affordable Homes Act with specific attention to the changes to state law regarding ADUs, the Home Modification Program, the Facilities Consolidation Fund, and other programs and legislative changes that could be leveraged to support affordable housing for individuals with ASD.

**Discussion on Next Steps for Subcommittee Work**

* The next Commission meeting is scheduled for December 9th, and it would be reasonable to ask subcommittees to come up with one or two priorities for the Commission members to review.
* Look at each priority and put in a framework that looks at the budgetary needs of the recommendation, the legislative changes and any other requirements to get the priority or recommendation implemented.
* The most valuable asset of the subcommittee work is that it brings together the various state agencies along with other stakeholders. Most of the time, state agencies work in silos – this work is bridging the gap between the state agencies. The value of the subcommittees in the connections of the state agencies.
* The work feels circular with no result at the end of the day. The subcommittees are doing good work but need more direction from the Commission. We make recommendations but don’t know where they go – we should focus on 1-2 recommendations/priorities during the year.
* Identify one big priority as there are themes across the subcommittee work – one shared priority for all subcommittee – or a few shared priorities.
* Allow subcommittees to go back and prioritize the work but we also need to look at acuity levels of individuals as there are gaps in the provider care for high acuity workers – there is a loss in the providers who were doing this work.
* Create a state-wide website and identify and work on certain topics – i.e. safety – it could be a Mass.Gov site offering information, opportunities, and training.

**Next Meeting**

* We could ask subcommittees to spend time on prioritizing recommendations and priorities – bring back top two to Commission with goals and the ability to accomplish it.
* Look at the common themes on each subcommittee recommendations/priorities.
* Look at a framework of putting each subcommittee recommendation/priorities in 3 buckets: short, medium and long-term.
* Continue this conversation at the next meeting and expand our next meeting to ensure that there is enough time for thoughtful discussion. We could also add an additional meeting prior to or after the December 9th meeting.
* The Undersecretary will work with the team on next steps. The expectation is that we look at the recommendations/priorities and come together on December 9th with a plan.

With no further business to discuss, there was a motion by Jessica Sassi to adjourn the meeting, Ms. Gardner seconded the motion. With no objections, the motion was passed and the meeting adjourned.