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Carolyn Kain Executive Director

THE MASSACHUSETTS AUTISM COMMISSION ANNUAL REPORT

March 2021

Autism Commission

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Commission Members

Michele Brait, Parent

Dan Burke, Arc of Massachusetts Representative

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Jo Ann Simons, Northeast Arc Representative

Vincent Strully, Jr., Chief Executive Officer New England Center for Children

Judith Ursitti, Autism Speaks Representative

Amy Weinstock, Autism Insurance Resource Center Representative

In accordance with Section 217 (c) of Chapter 226 of the Acts of 2014, "the Autism Omnibus Law", the Executive Director submits this annual report on behalf of the Autism Commission to the Governor, the Joint Committee on Children, Families and Persons with disabilities, and the Joint Committee on Health Care Financing.

The 2014 Autism Omnibus Law established the Autism Commission as a permanent entity, comprised of 35 members including; State Legislators, State Secretariats, State Agencies, Autism advocates and service organizations, and 14 individuals appointed by the Governor. The Secretary of Health and Human Services is the designated Chair of the Commission. The Commission has five (5) subcommittees, each co-chaired by a state agency member of the Commission and an appointed member of the Commission. The subcommittees are; 1) Birth to 14 years of age; 2) 14-22+/employment; 3) Adults; 4) Healthcare; and 5) Housing. The subcommittees meet monthly or bi-monthly.

The Autism Commission is charged with making recommendations on policies impacting individuals with Autism Spectrum Disorders ("ASD") and Smith-Magenis syndrome. The Commission is required to investigate the range of services and supports necessary for such individuals to achieve their full potential across their lifespan, including but not limited to, investigating issues related to public education, higher education, job attainment and employment, including supported employment, provision of adult human services, post-secondary education, independent living, community participation, housing, social and recreational opportunities, behavioral services based on best practices to ensure emotional well-being, mental health services and issues related to access for families of children with autism spectrum disorder and adults who are from linguistically and culturally diverse communities. ¹

This report provides updates on services provided to individuals with ASD and the recent recommendations of the Autism Commission established therein.

<u>Autism Prevalence</u>

In 2020, the prevalence of autism spectrum disorder ("ASD") for eight (8) year olds was reported by the CDC to be 1 in 54, with four times as many boys being diagnosed with ASD than girls.

<u>The 2014 Autism Omnibus Law</u>

The 2014 Autism Omnibus Law required: a) the creation of tax-free "ABLE" accounts for qualified disability expenses; b) a comprehensive program of community developmental disability services by the Department of Developmental Services; c) the Department of Developmental Services ("DDS") issuing of licenses to providers for individuals with developmental disabilities for a term of two years; d) the creation of an autism endorsement for special education teachers by the Board of Elementary and Secondary Education; e) Coverage by MassHealth of medically necessary treatments under the age of

¹ Chapter 226 of the Acts of 2014, Section 1(c)

21 including ABA services and augmentative and alternative communication devices, subject to federal financial participation; f) a plan between DDS and the Department of Mental Health to provide services to individuals who have both a developmental disability and a mental illness; g) and further investigation and study by the Commission on the issues of employment and higher education, and housing and h) Commission recommendations for plans of action for the Commonwealth on higher education and employment, and housing for individuals with ASD.

Updates on Autism Omnibus Law Mandates

- I. <u>ABLE accounts.</u> **Completed**. The Massachusetts Autism Omnibus Law called for the establishment of "<u>Achieving a Better Life" or "ABLE</u>" savings accounts for individuals with disabilities for qualified disability expenses. In May 2017, Massachusetts launched its ABLE accounts known as "The Attainable Savings Plan", established and will be maintained by the Massachusetts Education Financing Authority (MEFA) and by Fidelity Investments. The Attainable Plan is available to individuals with disabilities nationwide and allows qualified individuals with disabilities to save up to \$14,000 a year without jeopardizing their Social Security and Medicaid benefits.
- II. <u>Department of Developmental Services</u>. **Implemented and on-going.** The Department of Developmental Services ("DDS") was directed to develop a comprehensive program of community developmental disability services and to issue licenses to providers for a term of two years. DDS was also required to file annual reports reviewing its progress on the implementation of the law.

Since November 2014, DDS has been accepting applications for individuals with Autism Spectrum Disorder, Prader-Willi Syndrome, and Smith-Magenis syndrome. From November 2014 to October 2020, **2,746** "newly eligible" individuals with ASD <u>only</u> met the DDS criteria for eligibility as a person with autism <u>and</u> functional impairments (in three or more of seven life areas). Of the 2,746 individuals eligible **1,774** are enrolled in DDS services.

Individuals with an intellectual disability (ID) <u>and</u> 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 <u>and</u> ID. The number of new individuals with ID <u>and</u> ASD as of October 2020 is **1,291**.

The FY21 "Turning 22 budget" was submitted at \$25M. There are **362** individuals with ASD only in this year's Turning 22 class, which is 27% of the FY21 Turning 22 class. There are also **254 individuals with ASD and ID**, which is an additional 21% of the FY21 Turning 22 class.

T22 FY21 Class – Breakdown where

reported								
Race & Ethnicity*	ASD/ID	ASD Only	Total					
Missing Race	143	274	417					
ASIAN/PACIFIC								
ISLANDER	11	1	12					
BLACK OR AFRICAN								
AMERICAN	15	3	18					
CAUCASIAN	71	77	148					
MULTI-RACIAL/MIXED	2	4	6					
OTHER	12	3	15					
Total	254	362	616					

- III. <u>Autism Endorsement</u>. Completed. The Board promulgated regulations for an autism endorsement for licensed special education teachers, which included both coursework and field experience working with students with autism for this endorsement in June 2015, under 603 CMR 7.14(5). In 2017, the ESE Board voted to expand the autism endorsement to general educators.
- IV. Coverage of Medically Necessary Treatments by MassHealth. Implemented and On-going. The 2014 Autism Omnibus Law amended G.L. c. 118E, for MassHealth to cover, subject to federal financial participation, medically necessary treatments for persons younger than 21 years, including ABA services and supervision by a BCBA, and dedicated and non-dedicated augmentative and alternative communication devices, including but not limited to, medically necessary tablets.

MassHealth implemented statewide ABA services as of June 2015. MassHealth FY20 spending on ABA, total spent by ABA codes **\$121,215,751**. The number of individuals served is **3,162** for ages 0-5 years; **2,634** for ages 6-12 years; and **684** for ages 13- 20 years.

In FY20, MassHealth issued **36** dedicated speech generating devices (SGDs) and **3** non-dedicated devices. To date, in FY21 MassHealth has issued **21** dedicated SGDs and has **2** pending requests for non-dedicated devices. MassHealth plans to conduct a training for all SLPs that are enrolled in MassHealth, and to create a support line for consumers. MassHealth will work with the AIRC and MAC to identify and resolve any barriers with the processes for approval and issuance of non-dedicated devices (medical necessity criteria, evaluations, procurement and delivery), including any adverse impacts based on race, ethnicity, and primary language.

V. <u>DDS and the Department of Mental Health ("DMH"</u>). **Implemented and Ongoing**. DDS and DMH were required to develop a plan to provide services to individuals who have both a mental illness <u>and</u> a developmental disability. DDS and DMH entered into an Inter-Agency Agreement to collaborate in the development and funding of supports and services to individuals who are eligible for services from both agencies. The agencies are engaged in regular meetings and joint trainings. DDS and DMH have an Inter-Agency Agreement which expanded clinical expertise through 3 Fellowships since July 2016, one at UMass Medical, one at Mass General Hospital and one at Boston Medical Center. The fellowships had provided **81 consultations** to date resulting in diagnostic clarification, service needs, and treatment planning suggestions for individuals with ASD and mental health issues.

Update: For the 2019-2020 academic year (July to June): Combined, the sites recorded **21 evaluations of DDS/DMH clients** resulting in diagnostic clarification, service needs and treatment planning suggestions for individuals with ASD and mental health issues.

The Fellows are located at very active clinics and participate in additional evaluations and follow-up along with clinic staff. In addition, they have opportunities to participate in conferences, various publications, book chapters and presentations with other senior staff members, giving them significant clinical and research experience as part of the Fellowship.

VI. Further Investigations and Studies by the Commission.

a) **On-going Work.** The Omnibus Law also required the Commission to further investigate and study the higher education opportunities, employment training opportunities, and employment opportunities available to person with autism spectrum disorder, and to determine the current status of such higher education opportunities, employment training opportunities and employment opportunities, but not limited to vocational training programs for teen-aged and young adult persons with ASD and make recommendations for providing appropriate higher education, employment training and employment opportunities for the population of residents in the commonwealth diagnosed with ASD. Additionally, the Commission shall review the rise in the prevalence of autism spectrum disorder diagnoses among children in the past 30 years and shall make estimates of the number of children, aged 21 or younger, with autism spectrum disorder who will become adults in the coming decades and the resulting need for employment training and employment opportunities for those individuals and shall recommend a plan-of-action for the commonwealth in regard thereto.

- The 14-22/employment subcommittee of the Commission has been examining the higher education opportunities, employment trainings opportunities and employment opportunities for persons with ASD. The 14-22/ employment subcommittee is continuing its work on the need for higher education opportunities, employment trainings opportunities and employment opportunities to recommend a plan of action to the Autism Commission. The 14-22/employment subcommittee of the Commission has begun to study the higher education opportunities, employment trainings opportunities and employment opportunities.
- In FY20, MRC served **372 VR consumers with ASD** enrolled in postsecondary education. In terms of race and ethnicity these 372 are broken down as 326 white, 32 African American, 3 Native American, 119 Asian/Pacific Islander, and 18 Hispanic ethnicities.
- MRC has 35 providers of pre-employment services (Pre-ETS), which provide job exploration counseling, workplace readiness trainings, workplace learning experiences, counseling in post-secondary training opportunities and self-advocacy. In FY20 MRC referred **790 Vocational Rehabilitation consumers with ASD to its Pre-ETS vendors**. It should be noted that the MRC data system allows an individual to identify as more than one race/ethnicity. In terms of race and ethnicity these consumers are broken down in terms of racial/ethnic identifiers as 677 white, 91 African
 American, 58 Hispanic, 32 Asian/Pacific Islander, and 5 Native American ethnicities. During FY20, 344 individuals achieved successful employment outcomes during FY19, and 95.6% of individuals retained employment after placement to successful employment outcomes.
- b) In FY20, MRC **received 63 referrals through the 688 process** for individuals with ASD and served **265 individuals with ASD** in its Transition to Adulthood (TAP) program.
- c) **On-going Work.** The Commission on autism shall make an investigation and study of the present, and anticipated future, statewide affordable supportive housing needs for the commonwealth's population of persons with autism spectrum disorder. The Commission shall develop and conduct a statewide housing survey to determine the current status of affordable supportive housing stock for adults with autism spectrum disorder and shall make recommendations in regard thereto. Additionally, the Commission shall review the rise in the prevalence of autism spectrum disorder diagnoses among children in the past 30 years and shall make estimates of the number of children, aged 21 or younger, with autism spectrum disorder who will become adults in the coming decades and the

resulting need for affordable supportive housing for those individuals and shall recommend a plan-of-action for the commonwealth in regard thereto.

Based on the most recent 2020 prevalence data by the CDC of 1 in 54 and the 2019 Massachusetts census data, it is estimated that the number of individuals with autism who may need affordable supportive housing in the coming decades over the age of 18 could be 102,527. It should be noted that Massachusetts was not included in the CDC study on prevalence for autism. Massachusetts data from the Department of Elementary and Secondary Education for 2003-2015 show that the number of individuals with autism enrolled in special education rose during that 12-year period from 4,876 in 2003 to 18,572 in 2015.

The Housing Subcommittee Commissioned a state-wide housing survey by Technical Assistance Collaborative (TAC), as well as, reviewed information provided by the Housing Think Tank and other resources will provide the framework for the housing subcommittee to develop recommendations for the Autism Commission. The Housing subcommittee is continuing its work on the need for affordable supportive housing. The Housing subcommittee also reviewed with the DHCD representative on the subcommittee the design specifications on two projects underway on Cape Cod and discussed potential design additions to meet the needs of individuals with autism spectrum disorder.

Updates on the 2018 Recommendations of the Autism Commission

The Autism Commission developed new recommendations in 2018, updates are set forth below. The Autism Commission notes that there are recommendations included in the 2013 report of the Special Commission Relative to Autism that are not included in this report.

1. The Birth to 14 Subcommittee will collaborate with the Department of Elementary and Secondary Education ("DESE") on its development of their new electronic IEP to address issues that relate to students with autism spectrum disorder focusing on considerations of culture, race, linguistics, gender identity and socio-economic status.

• The Subcommittee will continue to keep this an ongoing recommendation for the upcoming year, as the IEP project is still in process. DESE will continue to keep the Autism Commission advised about the progress of the project.

2. MRC, DDS, and their respective employment providers will commit to strengthening their data collection processes to include retention data of one year for all individuals they

serve with autism spectrum disorder (ASD) focusing on considerations of culture, race, linguistics, gender identity and socio-economic status.

Update: Ongoing. In FY20 MRC referred 790 Vocational Rehabilitation consumers with ASD to its Pre-ETS vendors. It should be noted that the MRC data system allows an individual to identify as more than one race/ethnicity. In terms of race and ethnicity these consumers are broken down in terms of racial/ethnic identifiers as 677 white, 91 African American, 58 Hispanic ethnicities, 32 Asian/Pacific Islander, and 5 Native American. During FY20, 344 individuals achieved successful employment outcomes during FY19, and 95.6% of individuals retained employment after placement to successful employment outcomes.

DDS reported on data received from providers from April 2019 data that there were 2,462 individuals working in individual integrated jobs. The employment retention rate remained at 86% (employed 10 of last 12 months.) Recently DDS completed a shortened version of an employment snapshot report to get a better sense of the impact of COVID-19, which is being finalized now. Based on the reports of 83 providers, there were 2,708 individuals employed in individual integrated jobs as of March 1st, 2020. DDS is unable to compare retention due to the impact of COVID-19 because of the impact on numbers furloughed or laid off. DDS data does not currently differentiate by type of disability.

3. Additional and on-going trainings, focusing on considerations of culture, race, linguistics, gender identity and socio-economic status for MRC, DDS and their providers to support adult individuals with ASD focusing on considerations of culture, race, linguistics, gender identity and socio-economic status, including those who present with more challenging behaviors, to enable these individuals to work and be in their community with the proper supports.

Update: Ongoing.

4. ESE and DDS will identify best practices for educational and family supports focusing on considerations of culture, race, linguistics, gender identity and socio-economic status for transitioned aged youth with autism, including those who are behaviorally challenging and those who have co-occurring diagnoses through the following;

Update: Partially Achieve and Ongoing.

- 1. Achieved. Expanding the DESE/DDS residential prevention program. Additional funding has been provided to expand this program in FY20 from \$6.5 mil to \$10.5 mil.
- 2. Ongoing. Developing specialized curriculums to address the need for comprehensive sexual education. We will continue to collect data and work closely with DESE.

- 3. Ongoing. Strengthening linkages among state agencies (including DDS, MRC, DMH, DCF and DESE) and their community partners in order to coordinate and compliment services provided.
- 4. Ongoing. Exploring the possibility of implementing a "checklist" for the special education transition planning process to ensure the unique transition needs of the student are addressed.

5. Families of 20 to 30-year-old individuals with ASD (and no ID) who self-isolate in the family home need assistance and consultation services to help their adult family members to engage in their communities. DDS in collaboration with DMH develop and implement a family consultation initiative to address that need focusing on considerations of culture, race, linguistics, gender identity and socio-economic status focusing on considerations of culture, race, linguistics, gender identity and socio-economic status. This initiative would allow families and individuals with ASD, regardless of DDS or DMH eligibility, to have access to specialized expertise and technical assistance to address the needs of this segment of the ASD population. DDS and DMH will report annually to the Autism Commission on the implementation of this initiative.

Update: This work is on-going. DDS and DMH conducted a pilot program from January 2019-June 2019, to address the needs of 8 individuals (5 males and 3 females) with ASD who were self-isolating at home, each individual received up to 10 hours a week of services. Individuals made both small and larger gains due to the impact of pre-coaching services many of which are not easily quantified but clearly qualitatively real. These include:

- Acquisition of coping skills for anxiety
- Increased interest in social activities and positive community interactions
- Self-advocacy
- Applying for job including resume writing
- Increase awareness of public safety
- Increase in appropriate social skills including appropriate greetings and engagement in small talk

Based on the success of the pilot, DDS is going to procure a more expansive coaching service, consisting of three components: Pre-engagement, coaching, and college navigation. Due to Covid-19, DDS will reopen the procurement in the winter of 2021 with a start date in FY23. DDS has extended the current coaching contracts through 6/30/21.

6. The Adult Subcommittee will work with the Executive Office of Elder Affairs (EOEA) to gather information regarding that agency's involvement with aging individuals presenting with ASD focusing on considerations of culture, race, linguistics, gender identity and socioeconomic status, and collaborate with EOEA to ascertain if individuals with ASD known to or served by EOEA and/or their aging caregivers are aware of other services that may be available to individuals with ASD, and to ensure that EOEA's network of services are aware of the needs of individuals with ASD and receive training on how to address these needs. Update: This work is on-going. The Adult subcommittee continues to explore opportunities for collaboration with DDS and other state agencies with EOEA and to establish effective connections for older individuals with ASD and their aging caregivers.

7. DDS, in conjunction with DMH and MassHealth will develop and establish specialty ASD adult services that are designed and staffed to meet the needs of adults with ASD who present with severe challenging behaviors, including but not limited to: Day-Habilitation services, Community-Based Day Support services and other types of day services and specialized clinical support services necessary to effectively serve these adult individuals, and focusing on considerations of culture, race, linguistics, gender identity and socio-economic status.

Update: This work is on-going. The Adult subcommittee is continuing to examine the services currently available to service this population and current unmet needs. Several adult service providers have presented to this subcommittee and DDS has been asked to present on services available through its state programs. In the coming weeks, the subcommittee will focus on the potential for increased case management services.

8. Extend Mass Health coverage of medically necessary treatments for persons over the age of 21 who are diagnosed with autism spectrum disorder by a licensed physician or a licensed psychologist, said coverage shall include but not limited to, applied behavior analysis supervised by a licensed applied behavior analyst.

(MassHealth reports that the number of members 18-20 years of age who received ABA during FY17 is 45. MassHealth estimates the cost to expand ABA for individuals 21-26 years of age to range from \$483,358 on the lower bound up to \$4,189,105 on the upper bound. MassHealth does not have any current plan to extend coverage. MassHealth FY20 spending on ABA, total spent by ABA codes **\$121,215,751**.)

9. Expand training on autism spectrum disorders (ASD) and appropriate strategies for assisting individuals with ASD for health care providers focusing on considerations of culture, race, linguistics, gender identity and socio-economic status, including hospital emergency room personnel and residents.

Update – This remains a priority recommendation of the Subcommittee. A few hospitals have developed training programs and personnel that are promising models.

10. Expand Mental Health emergency and treatment services focusing on considerations of culture, race, linguistics, gender identity and socio-economic status to specifically address the needs of children and adults on the spectrum.

Update – MassHealth developed and implemented an ASD/ID specialty consultation for individuals with ASD/ID up to age 26 in behavioral health crisis. This consultation allows

Mobile Crisis Intervention ("MCI")/ Emergency Services Providers ("ESPs") and Emergency Department providers ("EDs") to get consultation from a licensed ABA during initial crisis evaluation and during follow-up. The clinical team can also access next-day consultation from a physician ASD expert. The program is managed by the Massachusetts Child Psychiatry Access Program (MCPAP) and provides 7-day per week coverage. Plans in 2021 include adding preventive consultation and outreach to families at high risk for crises.

The goal of the program is to increase the capacity and expertise across the Commonwealth to support children, adolescents, and young adults with ASD/ID and their families when they are in crisis.

11. The Housing Subcommittee of the Autism Commission will develop design guidelines that will meet the needs of individuals with autism spectrum disorder (ASD) to obtain and sustain tenancy in supportive affordable state funded housing units including those that; 1) currently exist; 2) are being rehabilitated; 3) and any newly developed units. The Housing Subcommittee will work with the appropriate state agencies and other stakeholders to review existing design guidelines and to develop additional guidelines that are necessary to meet the needs of individuals with ASD.

Update: On-going. The Housing subcommittee reviewed with the DHCD representative on the subcommittee the design specifications on two projects underway on Cape Cod and discussed potential design additions to meet the needs of individuals with autism spectrum disorder.

12. Initiate a statewide outreach and data collection on homeless adults with ASD focusing on considerations of culture, race, linguistics, gender identity and socio-economic status. The Subcommittee will collaborate with stakeholders to identify the number of adults with ASD who may be living in shelters or on the street. These efforts include;

- Contact Healthcare for the Homeless to request their assistance in identifying the number of adults with ASD living on the streets and amending the HUD questionnaire to include questions about disability and ASD diagnosis.
- Engage with the Inter-Agency Council on Homelessness to provide training on ASD and the states services that adults with ASD may be eligible to receive.
- Contact the Independent Living Centers to assess the number of adults with ASD utilizing this resource and their housing status.
- Conduct outreach to the Commonwealth's Continuum of Care (COC) Programs to collect data on the number of homeless adults with ASD

Update: On-going. The Subcommittee continues to explore the issues of individuals with autism spectrum disorder who are homeless and are accessing the shelter system on living on the streets. The Executive Director of the Autism Commission and the Manager of Program development worked with the Pine Street in to provide training on autism for its outreach workers who may encounter individuals with ASD. Bridge over Trouble Waters has also been contacted about training for its workers interacting with homeless youth who may have ASD.

13. The Department of Developmental Services (DDS) will collect data on the number of individuals who have; 1) been admitted to the Emergency Stabilization Unit at Hogan from their group home, 2) whether that individual returned to their current group home or transferred to another group home; and 3) length of stay. DDS will report this data quarterly to the Housing Subcommittee of the Autism Commission.

Update:

Current List of the ESU individuals with Autism from September 9, 2019- March 2020

Quarter	Individuals	From	Discharge	Length of Stay	То	Other
9/10/19 to 12/31/19	2	1 ER 1 Grp Home	No No			
1/1/20 to 3/31/20	2	2 from Grp Home	No/No			

14. The Workforce Development Subcommittee will work with the Board of Registration of Allied Mental Health and Human Services Professionals and the Division of Insurance to ensure that the licensure process for BCBAs and credentialing of LABAs by insurers is conducted in an efficient manner to enable LABAs the ability to provide approved services to families of individuals with autism spectrum disorder without unnecessary delay.

15. The Workforce Development Subcommittee will work with the Executive Office of Labor and Workforce Development and the Office of Immigrants and Refugees to promote employment opportunities at the EOLWD's Career Centers for direct care workers, and explore with the Department of Higher Education and the 15 MA Community Colleges the possibility of a loan forgiveness program for direct care workers to further support the need to increase the direct care workforce

<u>Other Priorities</u>

Birth to Fourteen Subcommittee

- 1. The priority of the Birth to Fourteen Subcommittee was to improve recruitment and retention strategies of BCBA's and related behavior therapists in public education Settings. *This work is on-going.*
- 2. The second priority of the Birth to Fourteen Subcommittee was to reduce wait times for evaluation and diagnosis of ASD. *This work is on-going.*

<u>Adult Subcommittee</u>

- 3. Continue to examine technological innovations to serve autistic adults receiving MassHealth and DDS services. Brainstorm pilots and activities, including discussions of stories from the community about uses of new technologies (here and in other states). Consider apps, use of robots, remote monitoring, and other technological advancements to enhance services, particularly in the context of work force crisis, the need to support aging caregivers in families, and development of independence. Review lessons from delivery of services during the pandemic should be discussed.
- 4. Discussion of how well the Individual Service Plan (ISP) process currently works for individuals served by DDS who are "autism only." Specifically, consider how some of the assessments, visioning statement and goal setting parts of the ISP process might require adjustment to better serve this population, and what appropriate time frames/cycles and levels of engagement of individuals and service coordinators might be. Discuss the results of the DDS North East Region pilot program for ISP process for this population (planned to end on 6/30/21) and approaches and experiences that other DDS regions are developing and testing.
- 5. Discuss the status of DDS coaching services RFR, including updates about the selection of providers and suggested data collection efforts about what may be meaningful to measure. Revisit the discussion of what was learned from 2019 pilot for self-isolating autistic young adults living with their families.
- 6. Present what was learned from the DDS/DMH RFI concerning supports for autistic adults with mental health needs, including a discussion of case management needs and intensive wraparound services and other clinical support needs. Focus discussion on coping and resiliency strategies to prepare for social changes out of individual control (e.g., Pandemic). Review and discuss programmatic supports that can be put in place to maintain social-emotional learning whether virtual or in person. Include discussion of anxiety and depression issues exacerbated by the COVID-19 pandemic or other isolating societal events.
- 7. Revisit the Information Card Initiative developed by DDS for better communication with the healthcare delivery system especially when presenting to the ED or in crisis. There will be a presentation of follow-up information about the

implementation and use of these cards/forms in hospital emergency departments, an initiative developed by this subcommittee in prior years. This will serve as a reminder for using these Information Cards.

New Recommendations

1. Covid Impact and Recovery Issues

The Autism Commission through its subcommittees examine the service delivery impacts of COVID-19 and recovery efforts needed, to maintain services that were beneficial to individuals with ASD and their families (i.e., telehealth, remote ABA services, family engagement), and to address adverse impacts to services (i.e., increased behavioral needs and hospitalizations, resource issues for PPE, internet access and remote challenges, need for adjustment to services to address regression and loss of skills), including inequitable impacts related to race, ethnicity, or primary language across age groups.

2. Access to Augmentative/Alternative Communication Devices for Children with ASD

The Autism Commission requests MassHealth provide data about children who have received dedicated and non-dedicated AAC devices, broken down by race and language spoken in the home. *This work is ongoing.*

3. Inclusion for Students with ASD

The Autism Commission requests that DESE provide data broken down by race, language spoken in the home and level of inclusion (full/partial/substantially separate) for students with ASD. *This work is ongoing.*

4. Children with ASD in DCF Care

The Autism Commission requests that DDS and DCF work to develop trainings for DCF staff about ASD. *The subcommittee has invited DCF to participate in its subcommittee meetings to discuss the individuals with ASD in involved with DCF or in DCF custody.*

5. Age of diagnosis data

The Autism Commission develop solutions so that data can be collected and reported on regarding the age of diagnosis of ASD broken down by race and primary language. *This work is ongoing.*

6. ASD students receiving extended school day services.

The 14-22/Employment Subcommittee will review any available data on extended school day services for individuals with ASD, access to after-school programs by individuals with ASD, and the number of school aged individuals with ASD accessing other out of school time services (DDS/DESE program).

The subcommittee will consider whether recommendations should be made regarding the potential role of extended day opportunities after-school and on the weekends in providing options in lieu of residential placements when appropriate and in preparing transition-age youth diagnosed with ASD for life in the workplace and community after their school eligibility ends at 22. The 14-22/Employment Subcommittee will evaluate ways to provide information to parents, self-advocates, and school districts related to the rights to extended day programming.

7. Licensure and Oversight of ABA Center-Based Programs

The Autism Commission recommends, for programs that are not otherwise already licensed by the state, that the state implement health and safety oversight, including possible licensure requirements and/or regulations, for ABA Center-Based programs operating in the Commonwealth.

The Autism Commission sent out a survey to known ABA service providers on December 10, 2020, regarding ABA center-based programs to inform this work.