

**March 2020**

**THE MASSACHUSETTS**

**AUTISM COMMISSION ANNUAL REPORT**

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Janet George, Ed. D., Representative with Clinical knowledge of Smith-Magenis Syndrome

Rosalin Acosta, Secretary of Labor and Workforce Development

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**Commission Members**

Michelle Brait, Parent

Dan Burke, Arc of Massachusetts Representative

Rocio Calvo, Ph.D., Boston College School of Social Work

Christine Hubbard, AFAM Representative

Dania Jekel, MSW, AANE Representative

Julia Landau, Esq., Massachusetts Advocates for Children Representative

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Teresa Schirmer, LICSW, Boston College School of Social Work

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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 six (6) 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]](#footnote-1)

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

***Autism Prevalence***

In 2018, the prevalence of autism spectrum disorder (“ASD”) for eight (8) year olds was reported by the CDC to be 1 in 59, with four times as many boys being diagnosed with ASD than girls.

***The 2014 Autism Omnibus Law***

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 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**

1. ABLE accounts. **Completed**. The Massachusetts Autism Omnibus Law called for the establishment of “Achieving a Better Life” or “ABLE” 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.
2. Department of Developmental Services. **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. The most recent DDS report was filed with the Legislature in February 2018.

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 2019, **2,261** “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). Of the 2,261individuals eligible **1,313** are 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 2019 is **1,041**.

The FY20 the “Turning 22 budget” was increased to $25.1 million. There are 311individuals with ASD only in this year’s Turning 22 class, which is **26%** of the FY20 Turning 22 class. There are also **191** individuals with ASD and ID, which is an additional 16**%** of the FY20 Turning 22 class.

1. Autism Endorsement. **Completed.** The Board of Elementary and Secondary Education was directed to provide an autism endorsement for licensed special education teachers, which included both coursework and field experience working with students with autism. The Board promulgated regulations 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.
2. 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 6/15. MassHealth FY19 spending on ABA, total spent by ABA codes **$109,171,065**. The number of individuals served is 3,014 for ages 0-5 years; 2,020 for ages 6-12 years; and 6,092 for ages 13- 20 years.

Since 2017, MassHealth has provided 6 non-dedicated devices to members with ASD, 4 to English (language) members, and 2 to Spanish (language) members. In June 2018, MassHealth issued an “FAQ” with guidance regarding non-dedicated devices. From SFY16-SFY19, MassHealth has provided dedicated devices to 532 members of all diagnoses; English 94% and Spanish 4%. In SFY19 there were 80 requests by members with ASD for dedicated devices and 54 were approved.

1. DDS and the Department of Mental Health (“DMH”). **Implemented and On-going**. DDS and DMH were required to develop a plan to provide services to individuals who have both a mental illness and 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 have provided **81 consultations** to date resulting in diagnostic clarification, service needs, and treatment planning suggestions for individuals with ASD and mental health issues.
2. Further Investigations and Studies by the Commission.
3. **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 for persons with ASD. MRC currently serves **279 VR consumers with ASD** enrolled in post-secondary education.  In terms of race and ethnicity these 279 are broken down as 247 white, 25 African-American, 3 Native American, 12 Asian/Pacific Islander, and 11 Hispanic ethnicity. MRC has over 30 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 FY19 MRC referred 994 consumers with ASDto its Pre-ETS vendors.  In terms of race and ethnicity these 994 are broken down as 842 white, 92 African-American, 9 Native American, 37 Asian/Pacific Islander, and 65 Hispanic ethnicity.  During FY19, 336 individuals achieved successful employment outcomes during FY19, and 93.1% of individuals retained employment after placement to successful employment outcomes.

1. In FY19, MRC **received 117 referrals through the 688 process** for individuals with **ASD**, and served **206 individuals with ASD** in its Transition to Adulthood (TAP) program.
2. **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.

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.

**FY20 Budget Highlights**

* Adult Autism funded at $30.7 million, a $12.6 million (70%) increase
* Children's Autism funded at $7.4 million, a $450,000 (7%) increase
* DESE/DDS Program funded at $10.5 million, a $4 million (62%) increase
* Turning 22 level-funded to FY19 at $25 million

***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.

* *A list of recommendations specific to the needs of Students with Autism Spectrum Disorders was developed by the Birth to Fourteen Subcommittee and sent to DESE in June. They were discussed with the DESE Dept. Office of Special Education Planning and Policy, and they concluded that the recommendations aligned with established goals for the IEP Improvement Project. Many of the suggestions made had already been incorporated. Documents to be updated include the IEP itself, A Special Education Guide, A process guide for writing the IEP, an annotated agenda for parents, and a Parent Guide to Special Education. 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 FY19 MRC referred 994 consumers with ASD**to its Pre-ETS vendors.  In terms of race and ethnicity these 994 are broken down as 842 white, 92 African-American, 9 Native American, 37 Asian/Pacific Islander, and 65 Hispanic ethnicity.  During FY19, 336 individuals achieved successful employment outcomes during FY19, and 93.1% of individuals retained employment after placement to successful employment outcomes.*
* *DDs reported that the number of individuals working in individual integrated jobs increased from 2,187 in 2017 to 2,309 in April 2018. The number of individuals currently employed who were employed for 10 of the last 12 months was 86%. 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. List of trainings provided in 2019*

* *The 14-22/Employment Subcommittee developed survey questions for MRC’s Pre-Employment Transition Services vendors, which were sent to providers on September 18, 2019, for the development of a training webinar facilitated by the Federation of Children with Special Needs and Boston Medical Center on November 14, 2019.*
* *DDS’s Autism 101 training was reviewed and updated edited by members of the Subcommittee. It is now under view by DDS. Once finalized, it will be presented in a webinar format and available to DDS employees on the DDS training platform.*
* *MRC has had a number of trainings for its employees with a focus on ASD which were facilitated by AANE. In addition, they hosted a 2 day event that focused on executive functioning – these trainings were for MRC employers. It was noted that AANE does not serve the ID/D population and that it is important to have a training that would include ASD with ID/D. According to the CDC, 31% of those diagnosed with autism spectrum disorder have a significant intellectual disability.*

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;

*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, meetings were held every 2 weeks with providers and in consultation with DMH. Seven (7) individuals consistently engaged throughout this pilot program. Of the 8 individuals, 7 engaged with the coaches on a regular basis. One individual had no engagement with the coach after an initial two hour meeting. After that, the coach made several attempts to engage this individual via phone, email, and text to no avail. Coaches scheduled meetings with individuals on a regular basis with a maximum of 10 hours per week, including non-direct collateral work on the individual’s behalf. The number of hours of service differed greatly between the two providers in part due to the difference in the structure of the two programs and the issues the individuals had. One provider had 117 hours of direct service for 4 individuals which included the two hours of service for one individual who did not participate after the initial meeting, meaning 115 hours of direct service. Provider B had 501.75 hours of direct service. Two of the individuals served by Provider B were outliers relative to the large volume of hours used. There were a total number of 324 in-person meetings with individuals and coaches spanning six months between January and June 2019. Thirty-three .six % (33.6%) of the meetings included a family member in the meeting with the individual. Typical meetings lasted 2 -3 hours. The individuals made both small and larger gains dues to the impact of the pre- coaching service 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*

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 socio-economic 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. A member of the EOEA agency participates on the Adult subcommittee and has provided a presentation on various services provided through EOEA to educate the subcommittee on the types of resources that may be available through EOEA to older individuals with ASD. 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 FY19 spending on ABA, total spent by ABA codes was $109,171,065 for individuals under age 21.*)*

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 – This remains a priority recommendation of the Subcommittee. The Children’s Mental Health Campaign has been working on a project to identify a model or models of urgent behavioral health care for the entire population to address this need. The Subcommittee has worked with the Campaign both collectively and as individual members, to incorporate the specific needs of people with ASD and their families into this model.*

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:*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| *Quarter* | *From* | *Discharge* | *To* | *Length of Stay* | *Other* |
| *1/1/18-3/30/18* | 1. *Family home* | *No* |  |  |  |
| *4/1/18-6/30/18* | *1 Residential School*  *------------------------------*  *1 Group Home* | *No*  *Yes* | *New Group Home* | *4 months* |  |
| *7/1/18-9/30/18* | *1 Group Home*  *1 Family Home* | *No*  *Yes* | *Group Home* | *7 months* |  |
| *10/1/18-12/30/18* | *1 Residential School*  *1 Group Home* | *No*  *Yes* | *Returned Same Home* | *9 months* |  |
| *1/1/19/3/30/19* | *1 Group Home* | *No* |  |  |  |
| *4/1/19-6/30/19* | *1 from Hospital*  *2 Group Homes* | *\**  *No* |  | *1 month* | *Deceased* |
| *7/1/19-9/9/19* | *2 Group Homes* | *No* |  |  |  |

*Summary: 13 admitted, 3 discharged, 1 passed away*

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.

***Other Priorities***

1. The first priority of the Birth to Fourteen Subcommitteewas to improve recruitment and retention strategies of BCBA’s and related behavior therapists in public education Settings. *This work is on-going.*

* *Update: The Birth to Fourteen Subcommittee created 2 surveys for input; one went to BCBAs and one to District Special Education Directors, which were distributed in June. 250 responses were received. The subcommittee began a review of the surveys and will be analyzing them further to determine next steps, possibly a quick resource guide for district leaders about helpful recruiting and retention practices. This will be an ongoing priority (but no formal recommendation at this time) for the subcommittee with further work to be done.*

1. The second priority of the Birth to Fourteen Subcommitteewas to reduce wait times for evaluation and diagnosis of ASD**.** *This work is on-going.*

* *Update: The Birth to Fourteen Subcommittee reviewed information gathered by DPH Early Intervention regarding wait times state-wide for evaluation and diagnosis, as well as updates on some pilot programs that are currently in place and expanding. The subcommittee will further explore information regarding the rate of delay in diagnosis and treatment broken down by demographics to address the issue of under-served populations and racial disparity within the system to assist us on this ongoing priority.*

**2019 New Recommendations**

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

That the Autism Commission request MassHealth to provide data about children who have received dedicated and non-dedicated AAC devices, broken down by race and language spoken in the home.

1. **Inclusion for Students with ASD**

That the Autism Commission request 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.

1. **Children with ASD in DCF Care**

That the Autism Commission request that DDS and DCF work to develop trainings for DCF staff about ASD.

1. **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.

1. **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.*

1. **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.

1. Chapter 226 of the Acts of 2014, Section 1(c) [↑](#footnote-ref-1)