**State Legislative Members**

Senator Joan Lovely, Second Essex-Beverly, Peabody, Salem, Danvers, and Topsfield

Senator Ryan Fattman, Worcester & Norfolk - Blackstone, Douglas, Dudley, Hopedale, Mendon, Milford, Millville, Northbridge, Oxford, Southbridge, Sutton, Uxbridge, Webster, and Bellingham.

Representative Christine P. Barber, Medford & Somerville

Representative Joseph McKenna, Worcester, Douglas, Oxford, Sutton, and Webster

**State Agency Members and Designees**

Marylou Sudders, Secretary of Health and Human Services, Chair

Carolyn J. Kain, Executive Director of the Autism Commission

Samantha L. Aigner-Treworgy, Commissioner of the Department of Early Education and Care

Rosalin Acosta, Secretary of Labor and Workforce Development

Sacha Stadhard, Manager, Special Grants and Youth Policy, *Designee*

Elizabeth Chen, Secretary of the Massachusetts Executive Office of Elder Affairs\

Kathryn Downes, Program and Policy Manager, *Designee*

Margret Cooke, Interim Commissioner of the Department of Public Health

Emily White, PhD, BCBA-D, LABA, Director Early Intervention Division Bureau of Family Health and Nutrition Department of Public Health

Brooke Doyle, Commissioner of the Department of Mental Health

Kathy Sanders, M.D., Deputy Commissioner for Clinical & Professional Services, *Designee*

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

Jennifer Maddox, Undersecretary, Department of Housing and Community Development

Bronia Clifton, DHCD Supportive Housing and Special Projects Manager, *Designee*

Elizabeth Morse, Deputy Commissioner Department of Development Services

James Peyser, Secretary of Education

Ann Reale, Undersecretary and COO for the Secretary of Education, *Designee*

Jeffrey C. Riley, Commissioner of Elementary and Secondary Education

Russell Johnston, Deputy Commissioner of Elementary & Secondary Education, *Designee*

Jane F. Ryder, Commissioner of Department of Developmental Services

Carlos Santiago, Commissioner of Higher Education

Mary Price, Coordinator, Department of Higher Education, *Designee*

Linda Spears, Commissioner of the Department of Children and Families

Katherine Canada, Assistant Commissioner, Services Network, *Designee*

Amanda Cassel Kraft, Assistant Secretary of MassHealth

Kate Ginnis, Senior Dir. of Child, Youth & Family Policy and Programs, *Designee*

James Vander Hooven, Ed.D., President, Mount Wachusett Community College

Toni Wolf, Commissioner of the Massachusetts Rehabilitation Commission

**Commission Members**

Janet Barbieri, AANE Representative

Michele Brait, Parent

Dan Burke, Arc of Massachusetts Representative

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

Christine Hubbard, AFAM Representative

Julia Landau, Esq., Massachusetts Advocates for Children Representative

Felix N. Martinez, Ph. D., Parent

Ann M. Neumeyer, M.D., Lurie Center Representative

Teresa Schirmer, LICSW, Boston College School of Social Work

Jo Ann Simons, Northeast Arc Representative

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

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**

The most recent prevalence of autism spectrum disorder (“ASD”) for eight (8) year olds was reported by the CDC to be 1 in 44, with four times as many boys being diagnosed with ASD than girls. Massachusetts was not one of the states studied by the CDC. Massachusetts data from the Department of Elementary and Secondary Education (DESE) for 2003-2021 shows that the number of individuals with autism enrolled in special education rose from **4,876** in 2003 to **24,640** in the 2020-2021 school year. <https://www.doe.mass.edu/InfoServices/reports/enroll/sped2021/disability.xlsx>

**The Global Pandemic COVID-19**

Since **March 10, 2020,** when Governor Baker declared a state of emergency due to COVID-19, and established a command center in March 2020, the Commonwealth has been responding to the impacts of a global pandemic on all its services. Decisions were based on on-going guidance issued over the last 23+ months by the Center of Disease Control (CDC), and guidance and protocols issued by state and local public health agencies. Services that have traditionally been provided to individuals with autism spectrum disorder in-person shifted because of the pandemic to virtual, remotely, and tele-health services, and have continued and continue to return in-person wherever possible with additional safety protocols (e.g., use of personal protective equipment, installation of air purifiers, and social distancing). The impacts of COVID-19 continue, and a recent surge of the Omicron virus required that Agencies and providers pivot again to ensure the health and safety of the individuals that they serve and their workforce.

The impacts of the global pandemic cannot be overstated or succinctly summarized. A list of certain key dates is provided below to highlight some of the changes and responses to the pandemic across our service delivery systems, and the resulting significant financial relief provided at the Federal and state level since March 2020. The work of the Autism Commission and its Subcommittees has been focused on helping individuals with autism adjust to the changes to services that occurred during the pandemic (largely remote with assistive technology) and returning to their in-person programming in accordance with CDC state and local public health agencies with safety protocols in place and eventually to pre-pandemic levels. Many programs experienced a decline in workforce/staffing as a result of the pandemic, and challenges persist with recruiting and retaining new staff. The Commonwealth has made significant financial investments to address this issue. Additionally, data from the 2019 annual report (before the pandemic) has been included this year, for a comparison of pre-pandemic data with current data as of October 2021.

**Certain Key Dates and Events During the State of Emergency Due to COVID-19**

**March 2020:**

* Schools close, which was extended several times through the school year ending in June 2020
* DCF moves to remote operations and continues in-person visits based on child/family needs and public health guidelines
* Daycare centers closed, emergency establishment of emergency childcare programs to provide care to vulnerable children and childcare of front-line workers
* Non-essential businesses closed
* Emergency childcare opened (350 sites)
* DDS site-based day programs closed; site-based supportive employment closed. DDS Residential Guidance and Visitation Restrictions implemented
* EOHHS announced **$95M** for residential service providers, a 10% increase over historical average monthly billing (November-January) for Tier 1 and Tier 2 contracted providers, including rest homes

**April 2020**:

* Order creating operation of emergency residential programs and emergency placement for children issued
* EOHHS announced **$44M** of additional funding across residential care service providers, bringing the total investment for these providers to $139 million during the COVID-19 public health crisis

**Re-openings begin In June 202 with Safety Protocols**

**June 2020**:

* Daycare centers began reopening
* Visitation for human services 24/7 congregate care programs expanded.
* Re-opening of DDS and MRC day programs begins with some programs reducing the number of individuals served in accordance with safety protocols
* DESE required districts to prepare plans for three learning models heading into the 2020-21 school year – in-person, hybrid, and remote – while prioritizing in-person models whenever possible
* Visitation at DMH youth programs
* **$16.1M in relief** for 32 special education residential school providers to support costs related to the COVID-19 pandemic. This funding is in addition to the **$3M** in funding the Department of Early Education and Care (EEC) provided in April to support the residential education school system
* DESE began distributing **$194.4M**through the Elementary and Secondary School Emergency Relief (ESSER I) Fund and **$182M** in School Reopening grants were issued last summer. DESE also provided nearly **$33M** to address remote learning technology needs and to provide students with adequate access to technology, including devices (e.g., Chromebooks), internet connectivity (e.g., wi-fi hotspots), and assistive technology, for use in remote learning environments during the 2020-21 school year. DESE has also provided districts and schools with additional supplies, including personal protective equipment, masks, and air purifiers. To date, DESE has distributed over 12,000 air purifiers and 1.5 million masks

**December 2020**

* Additional **$740M federal stimulus funds** (ESSER II) announced in, and the Governor’s proposed budget which fully funds the Student Opportunity Act, will enable districts to plan not just for immediate needs but also for long-term recovery and student acceleration. As part of the ESSER II package, DESE has committed additional resources to ensure that each district will receive a minimum of **$75,000** in ESSER II funds. DESE has also distributed **$4M** in supplemental funding to assist with the social and emotional needs of students. An even larger distribution of federal funds is expected as part of the pending American Rescue Plan

**April 2021**

* DESE required schools to use a full-time, in-person learning model for instructional hours to count towards structured learning time. This was staggered by grades from April to May, with High School eventually returning in May 2021

**December 2021-February 2022**

* DESE distributed **$79M** in federal stimulus grant funding in FY22 for “EAASES- Workforce”- Emergency Aid to Approved Special Education Schools to address workforce recruitment and retention

**FY21 Provider Relief:**

* 5.25% rate enhancement for congregate care - **$33M**
  + Approved in March 2021, effective July 1-June 30th, 2021
* 5.25% for DDS adult long-term residential ALTR July- Dec 2020 - **$60M**
* DDS Day Programs
  + Emergency retainer payments (40% and 25% of historical billings) paid August 2020-November 2020. Intended so providers could maintain staff and location in preparation for reopening

**FY22 Provider Relief:**

* ARPA identified Home Community Based Services rate enhancement 10% July 2021- June 2022 - **$676M gross** ($300 M net)- 90% of which must be directed towards workforce initiatives
* Non-ARPA Home Community Based Services rate enhancement 10% July 2021- June 202- **$110M** 90% of which must be directed towards workforce initiatives
* Inpatient Behavioral Health - **$31M** – supplemental rate increases July 2021-June 2022 for workforce recruitment and retention

**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 May 2017**.
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.

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** there were **2,261**“newly eligible” individuals with ASD only. In **October 2021**, there were **3,239** “newly eligible” individuals with ASD only who 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 2019, 1,313 individuals were enrolled in DDS services. Of the current **3,239** individuals eligible **1,934** 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. As of **October 2019**, there were **1,041** individuals with ASD and ID. The number of individuals with ID and ASD as of **October 2021** is **1,584**.

The **FY20** the “Turning 22 budget” was increased to **$25.1M** . There were **311** individuals with ASD only in that year’s Turning 22 class, which was 26% of the FY20 Turning 22 class. There were also **191** individuals with ASD and ID, which is an additional 16% of the FY20 Turning 22 class. The **FY22** “Turning 22 budget” was funded at **$79,948,997**. In previous fiscal years the DDS T22 budget was projected ONLY for individuals turning 22 in that specific fiscal year. As individuals become 22 years old during the year that they are enrolled in needed services including residential, Day and Work, Family Supports, etc. Annualized funds were then projected in the operational accounts specific to those services received (5920-2000, 5911-2000, 5920-2025 or 5920-3020).

In FY22 the Department adjusted the funding model to allow for more flexibility.  The second year, annualized amounts were projected to stay in the T22 account instead of being allocated across the operational accounts. This allows the Department greater time to refine and solidify placements before annualizing the funding in the appropriate account. The Turning 22 account now includes funding to support individuals for the first and second year.

For **FY22,** there are **343** individuals with ASD only in this year’s Turning 22 class, which is 28% of the FY22 Turning 22 class. There are also **257 individuals with ASD and ID**, which is an additional 21% of the FY22 Turning 22 class.

|  |  |  |  |
| --- | --- | --- | --- |
| **T22 FY22 Class Race & Ethnicity**  **(Self-Identified)** | **ASD Only** | **ID/ASD** | **Total** |
| Missing Race Entry | 263 | 142 | **405** |
| AMERICAN INDIAN/ALASKA NATIVE | 0 | 1 | **1** |
| ASIAN/PACIFIC ISLANDER | 4 | 6 | **10** |
| BLACK OR AFRICAN AMERICAN | 5 | 15 | **20** |
| CAUCASIAN | 63 | 85 | **148** |
| MULTI-RACIAL/MIXED | 0 | 5 | **5** |
| OTHER | 8 | 6 | **14** |
| **Total** | **343** | **260** | **603** |

1. Autism Endorsement. **Completed June 2015.**
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 Applied Behavioral Analysis (ABA) services and supervision by a Board-Certified Behavioral Analyst (BCBA), and dedicated and non-dedicated augmentative and alternative communication devices, including, but not limited to, medically necessary tablets.

MassHealth implemented coverage for ABA in June 2015. MassHealth **FY2019** spending on ABA was **$109,171,065**. In **FY2021**, MassHealth spent a total of **$140.5M** on ABA services for 6727 members. The breakdown of the ages of the children is found on the table, below.

|  |  |
| --- | --- |
| Age | # of children served |
| 0-5 | 3405 |
| 6-12 | 2,611 |
| 13-20 | 711 |
| Total | **6,727** |

In **FY21, MassHealth issued 74 dedicated speech generating devices (SGDs) to individuals with ASD and 7 non-dedicated devices**. Utilizing ARPA funding, MassHealth has developed a process to improve access to non-dedicated devices and has partnered with Mass Advocates for Children Speech Language Pathology providers to implement that process. This new process allows providers to maintain a stock of non-dedicated devices and cases to allow children to test them and, once authorized, get a device directly from their provider. MassHealth appreciates the partnership of the provider community and anticipates that this program will increase access to the devices.

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 had provided **81 consultations** by **October 2019**, increasing to**104 consultations** to **October 2021** 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 **23 evaluations of DDS/DMH clients** resulting in diagnostic clarification, service needs and treatment planning suggestions for individuals with ASD and mental health issues. Nine evaluations were conducted with the Massachusetts General Hospital Autism Spectrum Disorder Fellowship site and 14 at the UMass Memorial Health Center (UMMHC) Neuropsychiatry Clinic, Center for Autism and Neurodevelopmental Disorders (CANDO) site.

1. Further Investigations and Studies by the Commission.
2. **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 to recommend a plan of action to the Autism Commission.
* In **2019** MRC served **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. In **FY21**, MRC served **358 VR consumers with ASD** enrolled in post-secondary education.  In terms of race and ethnicity these 358 individuals are broken down as 313 white, 30 African American, 3 Native American, 16 Asian/Pacific Islander, and 17 Hispanic ethnicity. These individuals are enrolled in degree-bearing post-secondary education programs based on their latest Individualized Plan for Employment with MRC.
* During FY19, **336** individuals achieved successful employment outcomes during FY19, and 93.1% of individuals retained employment after placement to successful employment outcomes. For **FY21, 353** individuals achieved successful employment outcomes in MRC’s VR program, and **79.7%** of individuals retained employment after placement to successful employment outcomes. MRC also partnered with the Asperger/Autism Network (AANE) to provide training for MRC staff on best practices and strategies for serving individuals with Autism, including impacts of COVID-19 and remote work on individuals on the spectrum.

* 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 to students 14-22. In FY19 MRC referred **994** consumers with ASDto its Pre-ETS vendors. In FY21 MRC referred **983** Vocational Rehabilitation consumers with ASD to its Pre-ETS vendors, of which **543** received a work-based learning experience.  In terms of race and ethnicity these 983 individuals are broken down as 846 white, 107 African American, 12 Native American, 39 Asian/Pacific Islander, and 73 Hispanic ethnicity.
* DDS collects employment outcome data every year in the month of April from providers who deliver individual integrated employment services. This full data collection activity did not occur in 2020 due to the onset of the COVID-19 pandemic which had, and continues to have, a significant impact on the employment status of individuals supported by DDS. Similar to the general workforce, many individuals were furloughed, and some left their positions due to health and safety concerns. In **March of 2020** (pre-pandemic) there were approximately **2,700** individuals reported to be employed in competitive jobs. Based on the employment outcome data collected in **April 2021**, there were about **1,750** individuals employed, which represents an almost 30% reduction in the number of people employed. There continues to be employment growth since this data was collected in April as COVID-19 restrictions are relaxed, more people are vaccinated, and employment opportunities are opening up. In the past employment retention rates consistently clustered at about 86%, however, due to the impact of COVID-19, the most current retention rate is about 61% (defined as employed 10 of the last 12 months).

1. In **FY2019**, MRC received **117** referrals through the 688 processfor individuals with **ASD** and served **206** individuals with ASDin its Transition to Adulthood (TAP) program. In **FY2021**, MRC received **58** referrals through the 688 process(referral from special education before exiting school to adult agencies)for individuals with **ASD** and served **350 individuals with ASD** in its Transition to Adulthood (TAP) program, which is operated by the Independent Living Centers to provide peer-driven transition services to youths with disabilities. In terms of race and ethnicity these 350 individuals are broken down as 230 white, 26 African American, 22 Asian/Pacific Islander, and 62 Hispanic ethnicity. 2 chose not to disclose and 8 selected “other”.
2. MRC and its employment providers will continue to work on strengthening their data collection processes utilizing its MRC Connect integrated eligibility project and the agency’s project to develop a new and modern data system for its VR and CL divisions known as One MRC. These efforts will focus on including retention data for individuals served with autism spectrum disorder (ASD) as well as focusing on considerations of culture, race, linguistics, gender identity and socio-economic status in data collection and analysis.
3. **On-going Work.** The Omnibus Law also required the Commission to investigate and study 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 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), which was completed in June 2017, and provided an overview of the types of supportive affordable housing that may be available to individuals with ASD. The Housing Subcommittee also 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 and exploring the development of design guidelines to 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.

Based on the most recent ASD prevalence data by the CDC of 1 in 44 (8-year-old boys, and the 2020 Massachusetts census data of 7,029,917, it is roughly 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 159,770.

***On-going work of the Autism Commission and its Subcommittees***

Since 2018, the Autism Commission has developed new recommendations, and identified additional priorities for its Subcommittees to focus on and study over the next year for potential further recommendations. Current work and updates, where applicable, are set forth below. (*The Autism Commission notes that there were recommendations included in the 2013 report of the Special Commission Relative to Autism that are not included in this report.)*

**COVID-19 Impact and Recovery Issues**

1. In 2020, the Autism Commission recognized the need to 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. In addition to the Autism Commission’s work through its subcommittees to examine the impacts of COVID-19, Legislation was enacted in 2021, regarding this issue.

[Commission on Autism COVID-19 Study](https://budget.digital.mass.gov/summary/fy22/outside-section/section-124-commission-on-autism-covid-19-study) The commission on autism established in [section 217 of chapter 6](https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter6/Section217) of the General Laws shall investigate and report on the impact of the outbreak of the 2019 novel coronavirus, also known as COVID-19, on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color who have a diagnosis of autism spectrum disorder. The commission shall review all available data and information on the range of services and supports provided to individuals with autism spectrum disorder by each major racial and ethnic group, primary language, sex, and economic status during the outbreak of COVID-19. The commission shall make recommendations to address any inequities caused by the outbreak of COVID-19 including, but not be limited to, establishing periodic benchmarks and cost estimates for a coordinated system-wide response to address the inequitable impact of the outbreak of COVID-19 and the recovery process on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color with autism spectrum disorder. Not later than January 1, 2022 the commission shall submit a report of its investigation, including recommendations and any drafts of legislation necessary to carry those recommendations into effect, to the clerks of the house of representatives and the senate and the joint committee on children, families, and persons with disabilities.

*Update: This study has not been completed because COVID data has not been systematically collected based upon an individual’s diagnosis. The Autism Commission recommends that this data be collected and that the study be completed when the data is available.*

1. In addition, the Birth to 14 Subcommittee will examine the impacts of COVID-19 on students with ASD- to find solutions to the following issues: staffing shortages, compensatory service delivery, prioritizing in person learning, discipline rates, and family supports, with particular emphasis on prioritizing and addressing racial inequities that exacerbate each of those issues.

**ABA Center-Based Programs**

1. The Autism Commission recommended, 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.

*Update: Early Education and Care (EEC) is in the process of drafting regulations for the oversight and licensing of ABA center-based programs in the areas of health and safety and is currently conducting community engagement with stakeholders as part of this process.*

**Birth-14 Subcommittee**

1. The Birth -14 Subcommittee will examinethe issue oflevel ofinclusion for students with ASD (full/partial/sub separate)- broken down by race and language spoken in the home.

*Update: This information is included in Appendix A to this report.*

1. The Birth to 14 Subcommittee has requested that Early Intervention provide all available data related to the number of children with ASD in early intervention, the intensity of services being delivered, the percentage of in-person and remote service delivery, and that this information be broken down by race and language spoken in the home.
2. 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.

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

***14-22+ Subcommittee***

1. The 14-22 Years + Subcommittee will work with MRC, DDS, and their respective employment providers to strengthen their data collection processes to include retention data of one year for all individuals they serve with ASD focusing on considerations of culture, race, linguistics, gender identity and socio-economic status.

*Updates: Ongoing. In FY21 MRC referred 983 Vocational Rehabilitation consumers*

*with ASD**to its Pre-ETS vendors.  In terms of race and ethnicity these 983 are broken*

*down as 846 white, 107 African American, 12 Native American, 39 Asian/Pacific*

*Islander, and 73 Hispanic ethnicity.  During FY21, 353 individuals achieved successful*

*employment outcomes, and 79.7% 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.*

1. The 14-22 Years + Subcommittee will work to develop 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, including those who present with more challenging behaviors, to enable these individuals to work and be in their community with the proper supports.

*Update: On-going. MRC and DDS continue to work on assisting providers to support individuals with ASD.*

**Adult Subcommittee**

1. The Adult Subcommitteewill 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. Lessons from delivery of services during the pandemic should be discussed.
2. The Adult Subcommittee will continue todiscuss and examine 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.

*Update. Due to the impact of COVID-19 the Request for Response (RFR) for the new ASD services of Pre-engagement/Coaching and College Navigation was rescinded shortly after the March 16, 2020 posting. On August 26,2020, the RFR was rereleased on the Commonwealth’s Procurement website, COMMBUYS, with a new proposed provider qualification effective date of July 1, 2021. All existing pilot contracts for these services were extended to the end of the FY21 fiscal year, June 30, 2021. At the close of the procurement on October 13, 2020 the Department had received 21 responses from applicants seeking to become qualified providers for either Pre-engagement/Coaching and/or College Navigation. Four regional procurement committees reviewed the responses for their respective region to determine if applicants meet the criteria for qualification as outlined in the RFR. At the end of the qualification review, 19 of the 21 applicants were qualified, 14 were approved for both services, 3 were approved for Pre-engagement/Coaching only and 2 were approved for College Navigation only. There are at least 6 qualified providers in each region for these new services as of July 1, 2021. Since the start of the new fiscal year 10 of the qualified providers have been awarded contracts. As of 10/31/21, there are 188 individuals enrolled in Pre-engagement/ Coaching a slight increase from the 184 participants enrolled at the end of the fiscal year. The College Navigation pilot was capped at 30 participants last year and currently has an enrollment of 47 students.*

1. The Adult Subcommittee.will continue to examine 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.

**Healthcare Subcommittee**

1. The Healthcare Subcommittee previously recommended that MassHealth extend 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.

*Update: MassHealth does not have any current plan to extend coverage.*

*In FY2021, MassHealth spent a total of $140.5M providing services for 6,727*

*members up to age 21.*

1. The Healthcare Subcommittee will continue to explore the expansion of 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.*

3.*The* Healthcare Subcommittee will continue to focus on the expansion of 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 with ASD.

*Update: In 2020, 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.*

**Housing Subcommittee**

1. The Housing Subcommittee is working to develop design guideline recommendations to meet the needs of individuals with 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.

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

2. Housing Subcommittee. 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.

*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.*

3. Housing Subcommittee. 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: For CY2021, there are currently 5 autism individuals in the Emergency Stabilization Unit (ESU) at the Hogan Regional Center. There were zero admissions and there were 2 discharges to a group home. With their length of stay at the ESU being 1 year 3 months & 1year 8 months respectively.*

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