### THE OFFICE OF

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### LT. GOVERNOR KIMBERLEY DRISCOLL

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SECRETARY OF THE EXECUTIVE OFFICE
OF HEALTH AND HUMAN SERVICES

Carolyn Kain

**Executive Director** 

# THE MASSACHUSETTS AUTISM COMMISSION 2022 ANNUAL REPORT

May 2023

### **2022 State Legislative Members**

Senator Joan Lovely

Senator Ryan Fattman

Representative Christine P. Barber

Representative Joseph McKenna

### **2022 State Agency Members and Designees**

Marylou Sudders, Secretary of Health and Human Services, Chair

Carolyn J. Kain, Executive Director of the Autism Commission

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, 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

Amy Kershaw, Acting Commissioner Early Education and Care

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* 

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Noe Ortega, Commissioner of Higher Education

Mary Price, Coordinator, Department of Higher Education, Designee

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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

### **2022 Commission Members**

Janet Barbieri, AANE Representative

Michele Brait, Parent

Laurie R. Anastopoulos, LCSW, 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

### Introduction

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. <sup>1</sup>

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 **26,180** in the 2021-2022 school year.

https://www.doe.mass.edu/InfoServices/reports/enroll/sped2022/disability.xlsx

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<sup>&</sup>lt;sup>1</sup> Chapter 226 of the Acts of 2014, Section 1(c)

### **The Global Pandemic COVID-19**

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 2022.

As part of the <u>Chapter 24 of the Acts of 2021, the Fiscal Year (FY) 2022 budget</u>, the Commission was charged with conducting a study on Autism and COVID-19. Specifically:

The commission on autism established in <u>section 217 of chapter 6</u> 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.

The Executive Director of the Autism Commission met with representatives of the Department of Public Health (DPH), MassHealth, the Department of Developmental Services (DDS), the Massachusetts Rehabilitation Commission (MRC) and the Department of Elementary and Secondary Education (DESE) to determine the available data and information on the range of supports and services provided to individuals with autism spectrum disorder (ASD) by race and ethnicity during COVID-19. The respective agencies reported that they do not currently collect or possess the data for ethnicity and race to

identify any inequities caused by the pandemic and make recommendations to address them.

The Executive Office of Health and Human Services (EOHHS) committed to improving its data collection processes across our agencies in the areas of race and ethnicity. EOHHS recognized this need during the pandemic, and its agencies had already initiated efforts to review their data collection processes and to address the need for more data on race and ethnicity for the individuals it serves. A summary of current and future data collection efforts is explained below.

### <u>Department of Elementary and Secondary Education (DESE)</u>

DESE collects aggregate data on race and ethnicity, as well as low income for individuals with ASD. This data is included as **Appendices A, AA, B and BB** to this report.

### Department of Public Health (DPH), Early Intervention

DPH's Early Intervention Specialty Services providing Applied Behavior Analysis Services (ABA) for individuals with ASD collected data on race, ethnicity, spoken language, service hour utilization and telehealth services. This data is included as **Appendix C** to this report.

### The Department of Developmental Services (DDS)

DDS has begun the move to a new Case Management, Clinical and Claiming System (CMCCS) to replace its current system that will improve the capacity to collect and report demographic data. DDS has initiated agency-wide *process* and *training* efforts required for successful implementation, which includes:

- Creating new training and development opportunities about the value and importance of data collection/data integrity, for all management and SC staff.
- Using the new system (CMCCS) to develop new Intake and Eligibility business processes and rules that are paperless etc. and can record race/ethnicity/preferred language data at the time of enrollment.
- Targeted data clean-up efforts that are focused on confirming and/or recording <u>race</u> and <u>preferred language</u> data of our current population. In some areas, the race/demographic information is unknown for upwards of two-thirds of our population.
- Reviewing and making appropriate changes to the current case management system data dictionary (MediTech) for race categories (i.e. "Hispanic" to "Latin or LatinX") and will release these changes when the targeted effort is announced and distributed throughout the field.

### Massachusetts Rehabilitation Commission (MRC)

MRC is able to collect most of the data requested, especially for the Vocational Rehabilitation Program (VR) for individuals served with Autism.

- Race/Ethnicity of VR and Community Living (CL) Transitional Adulthood
- Program (TAP) and 688 consumers with Autism

- Gender (Male/Female/Chose not to identify) (VR)
- Age
- Primary Language (VR)
- Basic Services Provided (such as Job Placement, Counseling and Guidance, Benefits Planning, Training, Assistive Technology, job coaching, College education, Pre-ETS)
- Economic Impact (Employment placements and outcomes, wages/hours, public benefits such as SSI/SSDI, health insurance type)
- Data on race/ethnicity, employment outcomes, geographic location of individuals served, educational outcomes (i.e college graduation, high school graduation, enrollment in post-secondary, etc), gender, age, employment rate (successful vs unsuccessful outcomes), program dropout rate without employment.

MRC is developing a new data system for its two CL to collect similar data.

### MassHealth

As of September 28, 2022, the Center for Medicare and Medicaid Services approved an extension of Massachusetts' 1115 demonstration renewal. MassHealth is making equity a core pillar of value-based care in its 1115 waiver demonstration renewal. As part of this effort, MassHealth is working to improve collection of social risk factor (SRF) data including race, ethnicity, language, disability status, sex, sexual orientation, and gender identity (RELD-SOGI) in order to both better understand and address disparities faced by MassHealth members and also hold Accountable Care Organizations (ACOs) and hospitals accountable to reducing health disparities. MassHealth is prioritizing a member-friendly approach, including explaining the terms and why RELD-SOGI questions are being asked and selecting standards with a lens towards understanding of intersectionality and cultural competency. MassHealth has leveraged commonly cited national standards where available in order to allow for alignment across other health care partners and entities.

### 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**

- I. <u>ABLE accounts.</u> **Completed May 2017**.
- 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 2022, **3,835** "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). **As of October 2019**, **1,313** individuals were enrolled in DDS services. Of the **3,835** individuals eligible **2,247** are currently 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 2022** is **1,988**.

The **FY23** "Turning 22 budget" was funded at **\$84,099,551**. 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, 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 FY23, there are **412** individuals with **ASD only** in this year's Turning 22 class, which is **30%** of the FY23 Turning 22 class. There are also **278 individuals with ASD and ID**, which is an additional **21%** of the FY23 Turning 22 class.

FY23 T22 Class Members (ASD by Race)

Race	ASD Only	ID/ASD	Total
Missing Race Entry	290	149	439
ASIAN/PACIFIC ISLANDER	10	13	23
BLACK OR AFRICAN AMERICAN	5	20	25
CAUCASIAN	91	82	173
MULTI-RACIAL/MIXED	2	6	8
OTHER	14	7	21
UNKNOWN	0	1	1
Total	412	278	690

N.B.: DDS has begun a data improvement initiative for collection of race data for all individuals served.

### III. Autism Endorsement. Completed June 2015.

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. In **FY2022**, MassHealth spent a total of **\$185.4M** for 7,917 members whose age is broken down in the table, below.

Age	# of children served	
0-5	3,493	
6-12	3,457	

13-20	967
Total	7,917

In FY22, MassHealth authorized 125 dedicated speech generating devices (SGDs) to individuals with ASD and 2 non-dedicated devices (iPad). Utilizing ARPA funding, MassHealth has partnered with Mass Advocates for Children and Speech Language Pathology providers to develop and implement a process to improve access to non-dedicated devices. This new process will allow 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.

V. DDS and the Department of Mental Health ("DMH"). Implemented and Ongoing. 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 114 consultations to June 2022 resulting in diagnostic clarification, service needs, and treatment planning suggestions for individuals with ASD and mental health issues.

Update: For the **2021-2022 academic year** (July to June): Combined, the sites recorded **10** evaluations of DDS/DMH clients resulting in diagnostic clarification, service needs and treatment planning suggestions for individuals with ASD and mental health issues. Four (4) evaluations were conducted with the Massachusetts General Hospital Autism Spectrum Disorder Fellowship site and six (6) at the UMass Memorial Health Center (UMMHC) Neuropsychiatry Clinic, Center for Autism and Neurodevelopmental Disorders (CANDO)site.

- VI. <u>Further Investigations and Studies by the Commission</u>.
  - 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 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 FY22, MRC served a total of 3,089 Vocational Rehabilitation (VR) consumers with ASD overall. Of these, 557 are enrolled in Post-Secondary Education. In terms of race and ethnicity (assuming some identified as having two or more races), these 557 individuals in post-secondary education are broken down as 495 White, 38 African American, 7 Native American, 24 Asian/Pacific Islander, and 35 Hispanic. These individuals are enrolled in degree-bearing post-secondary education programs based on their latest Individualized Plan for Employment (IPE) with MRC.
- During FY22, 436 individuals with ASD served by MRC VR achieved successful employment outcomes, and 88.3% 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 Transition Services (Pre-ETS), which provide job exploration counseling, workplace readiness trainings, workplace learning experiences, counseling in post-secondary training opportunities, and self-advocacy to students aged 14-22. In FY22, 1,131 VR eligible consumers with ASD received services from its Pre-ETS vendors, of which 1,018 received a work-based learning experience. In

terms of race and ethnicity (assuming some identified as having two or more races), these 1,131 individuals are broken down as 988 White, 105 African American, 13 Native American, 53 Asian/Pacific Islander, and 83 Hispanic.

- b) In **FY2019**, 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. 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". In FY22, MRC received 190 referrals through the 688 process for individuals with **ASD** and served **359 individuals with ASD** in its **Transition to Adulthood (TAP) program**, which is operated by the Independent Living Centers (ILCs) to provide peer-driven transition services to youths with disabilities. In terms of race and ethnicity, these 359 are broken down as 275 White, 5 African American, 20 Asian/Pacific Islander, and 38 Hispanic ethnicity, as 19 chose not to disclose and 2 selected "Other".
- c) 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.

DDS, through a partnership with UMASS Boston Institute for Community Inclusion, collects snapshot employment outcome data every year in the month of April from providers who deliver individual and group employment services. 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 from 101 providers in April 2021, there were about 1,750 individuals employed individual jobs, and 1,122 individuals employed in group employment. Individuals were paid higher wages and worked more hours, even though the overall number of people working decreased since 2019. Individuals who worked in individual jobs were more successful at maintaining employment during the pandemic, and more individuals have returned to work in individual jobs. The more substantial impact on group

supported jobs during the pandemic suggests that this model of employment may not completely return to pre-pandemic levels and that more emphasis should be placed on individual jobs. There has also been a meaningful increase in wages for people working in both individual and group jobs. DDS is currently waiting for the final report summary from the 2022 April Snapshot Data.

d) **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 2021 Massachusetts census data of 6,984,723, 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 158,743.

### 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 recommendations 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.*)

### **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 to 14 Subcommittee**

### 2. **DESE IEP Improvement Project**

That the Birth to 14 Subcommittee will collaborate with the Department of Elementary and Secondary Education on its development of a new IEP to address issues related to students with autism spectrum disorder focusing on considerations of culture, race, linguistics, gender identity, and socio-economic status.

# 3. Access to Aided and Augmentative Communication (AAC) Devices for children with ASD

That the Birth to 14 Subcommittee will address barriers to obtaining and fully implementing dedicated and non-dedicated AAC devices for students with autism spectrum disorder by accessing available data from state agencies or other sources. They will review such data and determine next steps to improve equitable access and implementation (including assessment, training, and effective use of AAC devices across all environments).

### 4. <u>Inclusion for Students with ASD</u>

That the Birth to 14 Subcommittee will review statewide data on level of inclusion (full/partial/sub separate) for students with ASD disaggregated by race, language spoken in the home and determine next steps towards improving opportunities for inclusion.

### 5. **Age of Diagnosis**

That the Birth to 14 Subcommittee will review available information related to the age of diagnosis for children with autism spectrum disorder, particularly focusing on accessibility of assessments and wait list times and cross-reference information with other subcommittees as appropriate.

- That the Birth to 14 Subcommittee will invite members from the Department of Children and Families, the Department of Developmental Services, and the Department of Mental Health to participate on the subcommittee so that the subcommittee can continue to support the coordination of state agency services.
- 7. That the Birth to 14 Subcommittee will examine available information (with as much emphasis on pre- and post-pandemic data as possible) related to the transition of children with autism spectrum disorder from early intervention to special education, with a focus on the timeliness of this transition and the continuity of supports.

### 14-22+ Subcommittee

8. Recommendation Revised from 2019 – Approved by the 14 -22 Subcommittee on July 12, Final 2022

The goal of this recommendation is to provide additional opportunities for individuals with ASD for skill development and generalization of skills to avoid the need for a more restrictive setting, such as a residential school placement.

That parents be provided with information and educational materials regarding (1) their right to request longer day services to be considered as part of their child's special education IEP services, (2) potential after-school programming to enable students with ASD to participate in extracurricular/non-academic activities and community-based services along with their non-disabled peers, and (3) the DDS/DESE residential prevention program (subject to availability). The subcommittee recommends that this information be developed by DESE and the Federation for Children with Special Needs, with input from this subcommittee, as part of the Federation's Parent Training programs and materials.

### **Adult Subcommittee**

9. The focus of this recommendation is on the impact of the post-pandemic work force crisis on day and employment services for adults with autism:

That data be compiled from appropriate agencies (MassHealth, MRC, DDS) as to how many adults who were receiving day and/or employment services as of 3/1/2020 have not returned to such services as of 3/1/2023 or are not receiving the full complement that they previously received as of 3/1/2023. Pay particular attention to impacts on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color and any geographic differences.

That data be compiled from DESE and DDS as to the status of day, employment, and residential services as of 3/1/2023 for individuals with autism who Turned 22 during the pandemic, with particular attention to the impacts on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color and any geographical differences.

That data be examined to determine the degree to which high needs individuals with ASD are being particularly impacted by the workforce crisis because they require more intensive staffing. Working with the appropriate agencies, investigate measures that might be adopted to address the greater intensive staffing need and enhance salaries and wages to attract workforce for this subset of individuals served. Evaluate additional wage differential for residential cases, as well as alternative settings that provide respite or emergency support to individuals and programs during the crisis. This could include the need for a specialty behavioral health unit for these individuals.

- 10. That the Adult Subcommittee will work with the Healthcare Subcommittee of the Autism Commission, The Insurance Resource Center for Autism and Behavioral Health, MassHealth, and other appropriate agencies, as well as medical provider organizations to identify the source(s) of barriers to coverage of ancillary therapies encountered by adults with autism as they age and transition into Medicare. Determine if these barriers are unique to the autism community or encountered more generally by aging populations.
- 11. That the Adult Subcommittee identify steps to address any barriers for aging individuals with ASD who are transitioning into Medicare, including, if appropriate, requesting MassHealth to outreach to CMS and federal policymakers. The Adult Subcommittee will coordinate with the Executive Office of Elder Affairs (EOEA) on how to communicate effectively with aging Autistics.
- 12. That the Adult Subcommittee will identify and engage with a research group such as the Gerontology Institute at the University of Massachusetts Boston to mine Social Security data to generate prevalence estimates for the number of people with autism currently accessing Social Security in Massachusetts.
- 13. That the Adult Subcommittee will work with the Executive Office of Elder Affairs to offer training to staff at Senior Centers and other agencies that have direct

- contact with older adults. Train the staff to watch for aging families of adult autistics and seek permission to identify them to DDS, and to be able to refer them to resources to plan for when the last parent/family member dies.
- 14. That the Adult Subcommittee work with EOEA to develop and roll out a statewide program of future planning workshops for autism families not previously connected to future planning resources. Review currently available models and coordinate with family support centers, autism resource centers and adult day health programs that may be engaged in this work. Offer these workshops in partnership with local Senior Centers to identify and bring in as many aging families as possible.

### **Healthcare Subcommittee**

- 15. Autism Treatment Access and Coverage
  - Expand access to diagnostic resources for families.
  - Work with Early Intervention programs to ensure that children receive diagnostic evaluations for ASD prior to graduating from EI.
  - Expand ASD diagnostic training for general pediatricians to increase capacity and reduce waitlists
  - Coordinate efforts with Autism clinics to ensure that patients with more complex needs and profiles can be evaluated sooner.
  - Explore the feasibility of statutory changes to recognize ASD diagnoses by a wider range of professionals beyond the physicians and psychologists currently mandated.
- 16. The Healthcare Subcommittee recommends 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.
- 17. Expand Training of Healthcare Professionals
  - The Healthcare Subcommittee will continue to explore\_the expansion of training on autism spectrum disorders (ASD) and appropriate strategies for assisting individuals with ASD focusing on considerations of culture, race, linguistics, gender identity and socio-economic status.
    - Mental Health Mobile Crisis/Emergency Service providers
    - Community Behavioral Health Center staff

- Helpline/Hotline personnel
- Emergency room personnel and residents
- Hospital personnel and residents

### **Housing Subcommittee**

To assist with the development of additional 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, the
Housing Subcommittee recommends that the Autism Commission engage an
architect to assist the subcommittee with the review and submission of
additional design guidelines to support individuals with ASD in accessing
affordable supportive housing.