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Governor

Karyn Polito
Lieutenant Governor



Marylou Sudders
Secretary

Carolyn Kain
Executive Director

THE MASSACHUSETTS AUTISM COMMISSION 2018 ANNUAL REPORT

February 2019

Autism Commission



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Senator Richard Ross, Wrentham

Matthew Regan, Constituent Services Director, *Designee*

Representative Kimberly Ferguson, Holden

Representative Christine P. Barber, Somerville

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Marylou Sudders, Secretary of Health and Human Services, Chair

Carolyn J. Kain, Executive Director of the Autism Commission

Monica Bharel, MD, Commissioner of the Department of Public Health

Joan Kelly Rafferty, OTR/L, CEIS, Director of Specialty Services, Division of Early Intervention, *Designee*

Joan Mikula, Commissioner of the Department of Mental Health

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

Linda Spears, Commissioner of the Department of Children and Families

Katherine Canada, Ph.D., Assistant Commissioner, Services Network, Massachusetts Department of Children and Families, *Designee*

Russell Johnston, Senior Associate Commissioner, District Support for Elementary & Secondary Education

Janelle Chan, Undersecretary of the Department of Housing and Community Development

Bronia Clifton, Supportive Housing & Special Projects Manager, *Designee*

Toni Wolf, Commissioner of the Massachusetts Rehabilitation Commission

Carlos Santiago, Commissioner of Higher Education

Glenn Gabbard, Ed.D., Coordinator, Massachusetts Inclusive Concurrent Enrollment Initiative, Department of Higher Education, *Designee*

Patricia A. Gentile, Ed. D., President, North Shore Community College

Dan Tsai, M.D., Assistant Secretary of MassHealth

Laura Conrad-Laberinto, MSW, Program Manager, Office of Behavioral Health, MassHealth, *Designee*

Jane F. Ryder, Commissioner Department of Developmental Services

Elizabeth Morse, Deputy Commissioner, Department of Developmental Services

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

Rosalin Acosta, Secretary of Labor and Workforce Development

Jason Albert, Manager Special Grants, *Designee*

Other Commission Members

Cathy Boyle, Parent, Autism Housing Pathways

Michele Brait, Parent

Dan Burke, Arc of Massachusetts representative

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

Rita Gardner, Chief Executive Officer, Melmark

Todd Garvin, Self-Advocate

Christine Hubbard, AFAM representative

Dania Jekel, MSW, AANE representative

Patricia Jennings, Parent

Julia Landau, Esq., Massachusetts Advocates for Children representative

Susan Loring, RN, Director Autism Resource Central

Chris Supple, Attorney, Parent

Judith Ursitti, Autism Speaks representative

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

Teresa Schirmer, LICSW, Boston College School of Social Work

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; 5) Housing; 6) and Workforce Development. The subcommittees meet monthly or bi-monthly.

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

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

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

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

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

Updates on Autism Omnibus Law Mandates

- I. **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.
- II. **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 November 26, 2018, **1,853** “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 **1,853** individuals eligible **1,029** 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 November 26, 2018 is **759**.

The FY19 the “Turning 22 budget” was increased to \$25.1 million. There are **267** individuals with ASD only in this year’s Turning 22 class, which is **22%** of the FY19 Turning 22 class. There are also **102** individuals with ASD and ID, which is an additional **9%** of the FY19 Turning 22 class.

- III. 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.
- IV. Coverage of Medically Necessary Treatments by MassHealth. Implemented and On-going. The 2014 Autism Omnibus Law amended G.L. c. 118E, for MassHealth to cover, subject to federal financial participation, medically necessary treatments for persons younger than 21 years, including ABA services and supervision by a BCBA, and dedicated and non-dedicated augmentative and alternative communication devices, including but not limited to medically necessary tablets.

MassHealth implemented statewide ABA services as of 6/15. MassHealth FY18 spending on ABA, total spent by ABA codes **\$58,856,157**.

- V. 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 **50 consultations** to date resulting in diagnostic clarification, service needs, and treatment planning suggestions for individuals with ASD and mental health issues.
- VI. Further Investigations and Studies by the Commission.
- a) **On-going Work.** The Omnibus Law also required the Commission to further investigate and study the higher education opportunities, employment training opportunities, and employment opportunities available to person with autism spectrum disorder, and to determine the current status of such higher education opportunities, employment training opportunities and employment opportunities, but not limited to vocational training programs for teen-aged and young adult persons with ASD and make recommendations for providing appropriate higher education, employment training and employment opportunities for the population of residents in the commonwealth diagnosed with ASD. Additionally, the Commission shall review the rise in the prevalence of autism spectrum disorder diagnoses among children in the past 30 years and shall make

estimates of the number of children, aged 21 or younger, with autism spectrum disorder who will become adults in the coming decades and the resulting need for employment training and employment opportunities for those individuals and shall recommend a plan-of-action for the commonwealth in regard thereto.

- b) 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. 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 **FY18 MRC referred 960 consumers with ASD** to its Pre-ETS vendors. In terms of race and ethnicity these 960 are broken down as 850 white, 82 African-American, 9 Native American, 35 Asian/Pacific Islander, and 76 Hispanic ethnicity.
- c) In FY18, MRC **received 132 referrals through the 688 process** for individuals with **ASD**, and served **206 individuals with ASD** in its Transition to Adulthood (TAP) program.
- d) **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 to recommend a plan of action to the Autism Commission.

2018 Recommendations of the Autism Commission

The Autism Commission has developed new recommendations to highlight in the 2018 report, as outlined 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. *(DESE reports that there is no estimated cost for this work as ESE is in the process of updating its IEP system)*
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. *(DDS does not anticipate any increased cost for this. DDS will leverage existing data systems)*
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.

(DDS estimates that the cost of 2 days of trainings with speakers, space, etc. would be \$7.5K for each of the 4 Regions or \$30K statewide per year. In addition, DDS will expand its DDS Learning site.)

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;

- Expanding the ESE/DDS residential prevention program;
(DDS estimates that given average cost per student is about \$14K increasing this program by 100 would be approximately \$1.4M)
- Developing specialized curriculums to address the need for comprehensive sexual education;
(The subcommittee is exploring if there are any existing curriculums to address this need. ESE estimates a cost for developing this type of curriculum would be \$50,000 to \$100,000.)
- Strengthening linkages among state agencies and their community partners;
and
(There is no cost estimated for this work)
- 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.
(There is no cost estimated for this work, it is expected this tool can be developed by the subcommittee)

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. 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.

(DDS estimated cost to serve an estimated 8 individuals per Region for a total of 32 individuals statewide who would need these intensive coordinated services would be \$142,300/region or \$569,728 statewide per year)

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 EOE's network of services are aware of the needs of individuals with ASD and receive training on how to address these needs. *(These is no expected added cost for this work, a representative from EOE has joined the adult subcommittee and will provide a presentation on their network of services.)*

7. DDS, in conjunction with DMH and MassHealth develop and establish specialty ASD adult services that are designed and staffed to meet the needs of adults with ASD focusing on considerations of culture, race, linguistics, gender identity and socio-economic status 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.

(DDS estimates the cost to serve an estimated 225 individuals with challenging clinical needs at \$46,500. each would be about \$10.4M per year.)

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.)

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.

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.

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.

(DHCD reports that the initial environmental scan of the design guidelines could be done with state agency personnel and members of the Housing subcommittee. If outside assistance becomes required for this task DHCD estimates it would cost about \$5,000. Additionally, DHCD estimates that to develop additional guidelines or making refinements to those that exist would like cost about \$10K-\$15K.)

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 will 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

(The Housing subcommittee will contact these entities to explore the possibility of these data collection efforts. There is no cost estimate associated with these efforts at this time.)

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.

(DDS does not anticipate any additional cost for this report gathering.)

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.

(There is no estimated cost associated with this recommendation at this time. The Board of Registration has committed to addressing this need and the Division of Insurance has offered it assistance for any insurers not completing the process within a reasonable amount of time.)

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.

(There is no estimated cost associated with the effort to collaborate with state agencies to promote employment opportunities for direct care workers. Further exploration with higher education is necessary to determine if a loan forgiveness program is possible and related future costs.)